

**Bangor University**

## **DOCTOR OF PHILOSOPHY**

### **Surfacing the Perspective of Autistic Girls Aged Between Thirteen and Eighteen Within a Complex Social Discourse on Autism: A Qualitative Inquiry**

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Surfacing the Perspective of Autistic Girls  
Aged Between Thirteen and Eighteen  
Within a Complex Social Discourse on  
Autism: A Qualitative Inquiry

**Bethany Anne Edwards**

July 2022

## Declaration

'Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw'r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o'r blaen ar gyfer unrhyw radd, ac nid yw'n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deuol cymeradwy.'

Rwy'n cadarnhau fy mod yn cyflwyno'r gwaith gyda chytundeb fy Ngrichwyliwr (Goruchwylwyr)'

'I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.'

I confirm that I am submitting the work with the agreement of my Supervisor(s)'

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## **Dedication**

This thesis is dedicated to the autistic community I have engaged with through my personal and academic experiences.

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## Abstract

**Background and aims:** This thesis aimed to explore how autistic teenage girls are viewed within research, and how they are portrayed in the media; these insights were used to develop a co-produced study that aimed to illuminate the social world of autistic teenage girls, and then use these findings to improve their experiences. This addresses a gap in the literature focused on presenting the lived experiences of autistic teenage girls in research, including the impact being autistic has on their social worlds. The established tradition of research focussing on autism from the predominant perspective of autistic males is shifting, and an increasing number of contemporary researchers recognising and acknowledging the existence of a more variable presentations of autism. For example, explorations into why females were more likely to receive a later diagnosis of autism, or not receive a diagnosis at all, illuminated what many people already knew from their first-hand experiences – that there could be a different presentation of autism in females. Asking and listening to what autistic people have to say about their autism and experiences has been a further step in ensuring that research priorities reflect the needs of the autistic community, but some social groups are under-represented. The research presented in this thesis focuses specifically on one such group – autistic teenage girls. In this way, this study engaged and collaborated with autistic girls and other key stakeholders, including families, to address the under-representation of this group.

**Method:** This study used qualitative inquiry across three interrelated phases to explore the complex social discourse on autism, specifically, teenage girls aged 13 to 18. This consisted of a scoping review of 29 academic research articles guided by Arksey and O'Malley (2005), a discourse analysis of news publications across periods in 2015 and 2019 guided by Willig (2013), and a coproduced version of the 'one-page' profile. A total of 19 stakeholders were involved in the co-produced phase which utilised live workshops, email contributions and written comments as data sources. Each phase was developed in response to the evolving understanding of autistic teenage girls' experiences, reflective of an iterative process.

**Results:** Overall, the main findings from the scoping review indicated that autistic teenage girls are positioned as subjects to the research process. The thematic analysis highlighted topics such as *camouflaging*, and that

research focussed on measuring the occurrence of experiences rather than understanding them. The discourse analysis of news items sampled from 2015 and 2019 indicated that teenage autistic girls are positioned as the source of news and entertainment, with a preference for second-hand accounts; wider discourses such as 'models of disability' were also identified. These findings were used to design an empirical phase that utilised a participatory co-production approach in order to re-position autistic teenage girls as experts of their social world. The data from the co-produced phase was used to develop a co-created version of a 'one-page profile' tailored for autistic teenage girls. A 'one-page profile' captures all the important information about a person, applying person-centred thinking, values, and skills in a practical way. They are written by the individual, at times with support of people who know them, and can be used across education, health, and social care environments.

**Conclusion:** This thesis developed an account of a complex social discourse and co-constructed a version of the 'one-page profile' for autistic teenage girls as an outcome. It highlighted how autistic teenage girls experienced the social world in unique ways. Involving autistic people and other key stakeholders is crucial in understanding what these experiences are, so that research and services are not only about them, but for them too. This is of particular importance for the development of services aimed at supporting or improving health and well-being.

## Language glossary

Term	Description
Autistic	Encompassing all diagnostic labels, e.g., ASD, Asperger's.
Adolescence	Young people between the ages of 13 and 18.
Social world	The environments and spaces individuals experience.
Diagnosis	Receiving a diagnosis following an assessment – usually a multi-disciplinary team using diagnostic criteria (e.g., DSM V).
Female	Sex assigned at birth.
Gender	The gender of focus is females – rather than focusing on gender as a social construct.

### **Reflexive Preamble**

I, as an autistic researcher am situated within the community of participators that engaged with the study, and therefore was able to explore my position in relation to the research topic focus, that is, autistic teenage girls. As a researcher, I was determined to create a study design which allowed for the authentic voice and experience of autistic teenage girls, rather than conduct research with pre-determined and quantifiable outcomes. By utilising core components of the Positioning Theory (Harré & van Langenhove, 1991), which maintains that social action seeks to highlight explicit and implicit assumptions and beliefs ascribed towards others (Harre *et al.*, 2009), I formulated a participatory approach that viewed autistic people as stakeholders rather than participants. I felt it was necessary to engage with additional stakeholders, such as professionals and families, in order to facilitate a dialogue in relation to an understanding of the real world scenario for autistic girls within a wider social context.

This initial reflexive piece seeks to present my autobiographical journey that led to this research study being conducted. Overall, reflexive accounts broadly seek to provide an additional insight into the position and experiences of the researcher that underpin the rationale of any study (Gentles, Jack, Nicholas, & McKibbin, 2014). This reflexive process will be embedded throughout this PhD thesis and will highlight how my position as an autistic female and researcher, contributed to decisions made in relation to this unique qualitative enquiry.

When I spoke informally to a range of stakeholders about being a PhD candidate who wanted to explore the lived experiences of autistic girls between the ages of 13 and 18 years, several questions and comments came up frequently. These included assumptions concerning the reasons why the topic focus had been selected and the motivation for this, as well as what was hoped to be achieved. I am part of the autistic community, yet I had a varied response from those within the autistic community and in the wider arena of professional involvement, who either viewed the aims of the study as a beneficial contribution or commented that the motivation for the research was selfish or served a self-fulfilling purpose. These initial discussions expanded to

generate further questions concerning finding a reason as to why a young autistic girl may experience barriers and seeking to find a solution, as well as investigating the environmental and social worlds that young autistic females reside in. Finally, comments ranged from those that questioned the value of the research and the perceived scientific quality of the findings, to those that were surprised at the approach and methodology that would be implemented. This surprise appeared to stem from the wider expectation of research needing participants to be 'studied,' rather than engaging with stakeholders to explore lived experiences and drive change. I, therefore, felt that it would be appropriate to frame the research focus within a reflexive account, based on three areas:

- being a member of the autistic community
- the researcher's childhood and home environment
- a shift in awareness of how research can be implemented in relation to the concepts of 'scientific evidence and bias'.

These will be discussed in the first person to reflect the autobiographical style of discussion.

### **0.1 Being a member of the autistic community**

As a decision maker in the research conducted, it is important that my position as an autistic female is presented. Whilst no longer in the life stage that was the topic focus, I have first-hand experience of obtaining a diagnosis of Autism late in development (aged 17), that provided me with a unique insight and appreciation for the narratives that stakeholders were willing to share.

Being autistic means that the boundaries between this study and my personal life are not clear cut, as autism features predominantly in both. Through reflection, I now identify this as a positive factor during my PhD study, providing a motivation to continue and reinforcing that I was doing something worthwhile, whilst at the same time, utilising the unique abilities of an autistic person (sometimes referred to as special interests). Furthermore, being an autistic female helped gain the trust of the stakeholders, as they perceived me to have an innate understanding and relevant knowledge of the world of young autistic girls.



Whilst not dismissing the spectrum of autism, being able to share my own experiences created a safe space for others so share theirs, even if they were different or opposite to my own. Being open with stakeholders about my position as an autistic researcher was important to me, as I felt that not doing so would not allow me to be autonomous and result in a barrier being placed between myself and stakeholders. I find it interesting that the barrier of non-disclosure, as I saw it, was the opposite of my own and other stakeholders' experiences in their lives. Drawing to the purpose of why I pursued this level of study, to use research to improve the well-being and experiences for autistic teenage girls, it felt though my duty was to be open and honest. Through my own experiences in education, I have witnessed the perception of hierarchy, power, and tokenism in engaging with young people, as such, identifying roles in the research process was important. In identifying roles, there is the need to define the bounds of these roles and reflect upon them to ensure that these are followed. For me, acknowledging the perceptions of the autistic community about research was important in evaluating how I conducted myself and the research.

During my PhD, I have engaged on a personal level with conferences and events, where I openly discuss the impact being autistic has on me, from home life to education. Through this, I recognised how I would approach a topic differently when presenting to a non-autistic audience, than to an autistic audience. The exact reason for this still perplexes me, though this only went to reinforce the importance of being open with stakeholders, especially autistic stakeholders when asking about their experiences and thoughts on research.

## **0.2 Childhood and home environment**

From an early age I was encouraged to put my full effort into all tasks that presented. I was supported to understand concepts that were illogical to me, as well as provided with the tools to navigate these without presenting any difficulties. Growing up in a loving environment where I was accepted certainly influenced the adult and researcher I have become, specifically, in trusting my judgement and standing up for things I believe in. Whilst during much of my childhood and teenage years I did not have any

explanation for what can now be viewed as indicators of being autistic, my parents support in overcoming barriers certainly influenced my compulsory educational attainment. Nonetheless, retrospectively, I am certain that should I have had the understanding and support that I have now, I not only would have achieved higher grades, but also experienced less adversity in my teenage years.

I am cautious that I do not present an overly censored representation of this time, as there were barriers and many challenges during this time, but I felt it important to acknowledge the context in which I grew up. With a focus on education, I had topics I enjoyed, mainly mathematics, but nothing really grabbed my interest and attention, so activities became purely for conventional purposes of getting it done. Whilst on the surface it may have appeared to others that I was relatively gifted academically, they did not see the time put in to get to that or the support from my parents. A specific example is during A level Maths I was struggling to engage with the teaching style from one teacher, so my father taught himself the curriculum so he could adapt it and teach me in a way that suited my learning preferences. I consider this example to reflect how I conceptualise my diagnosis, which is explained in a quote I read early after my diagnosis when trying to find information about what this new word I had been introduced to meant:

*‘...autism is like running on Windows while everyone else is a Mac...’ (Anon)*

Experiencing the challenges with not understanding why my brain is the way it was resulted in consequences on my mental health. Acknowledging that there was something that meant my brain was wired this way was a huge relief and what many of my non-autistic family describe as a ‘lightbulb moment’. Several years on from my diagnosis, I know how I work best, I know what conditions I need to succeed, but most importantly, I know my limits. Without presenting diagnosis as a lifesaving event, it most definitely was a life altering one that set me on a path of discovery, learning, and acceptance. To this day, my family ethos and support has enabled me to overcome challenges with ‘adulthood’, encouraging me to push myself, whilst not being too hard on myself when I find things hard. Big life events such as moving to university, learning

to drive, starting a new job, renting a house are things I have achieved, and all shaped the person and researcher I am today.

### **0.3 Shift in awareness of research and concepts of 'science'.**

After twenty years in continuous education an understanding of scientific rigor and perceptions of 'expertise' have only recently fully shifted to the position in which I find myself today. Throughout primary and secondary education, there was always another actor that was the expert in the topic being discussed, whether this be a teacher or a prescribed textbook. These positioned the view of knowledge as being one-dimensional and static, rather than objective and fluid. This continued much into my undergraduate education, where the idea of qualitative methodologies such as interviews seemed extreme and exciting. Through my early postgraduate research experience, the doors started to open into the vast array of research styles and methods that were available to me. Nonetheless, I did not feel comfortable to go beyond these bounds which had somehow been imposed onto my positioning through perceptions of best practice and highlighting specific tools and approaches being gold standard.

Subsequently to completing my Master's in Research, I made the shift from the School of Education to the School of Health Science, a move that outsiders often pondered and questioned. This new department brought with it a new understanding of the bounds of research, with the methods and techniques that were available to me as a first year PhD candidate being extremely exciting. I felt that I had found my 'place' and had the environment to support me in becoming an independent researcher.

Whilst the road to the adoption of participatory methods and iterative processes within the research study was gradual, it was an enlightening journey and one which demanded the development of my own reflexivity. Questions focused on 'Why am I doing this? What am I doing this for?' were a recurring theme whenever I needed to make a decision or when I questioned my capabilities. Having this new perspective on research at times was overwhelming, as I wanted to know more about everything, so

balancing that excitement was a challenge. For me, organisation, structure, and predictability are things I value and find incredibly important. Though when it came down to this PhD, I did not get the excitement or buzz about these things, the idea of iterative processes and coproduction filled me with excitement. I must admit, at times, I found myself asking why did you not do the safe predictable approach? Why did you give yourself this pressure and stress? I yet am to fully give myself an answer for these questions, or be able to articulate one in this reflection, though a likely influence was the desire to conduct research that was responsive to the autistic communities priorities rather than to complete research in order to gain a PhD. For me, from the early application stages to these final reflections, a PhD has been a mechanism to complete research, with the resources, expertise and institutional credibility enhancing the contributions of this study.

#### **0.4 Summary**

This PhD is the latest leg of my education, and will no doubt be the last. It has been the most enlightening on a personal and professional level, whilst also reaffirming that I am capable and should have confidence in my instincts. Whilst exploring the new or different goes against my innate autistic gravitational pull, my reflexivity, and its positive influence on my research, is something that I hope will continue. Reflexivity is embedded throughout the thesis to acknowledge the role of my personal experiences and positions on the phases.

## **Chapter 1: Introduction**

### **1.1 Unique contribution to knowledge**

This thesis aims to contribute a unique perspective of autistic females' perception of the social world as well as priorities for research. Furthermore, it utilises approaches not previously used in the study of autistic teenage girls. Due to the Coronavirus pandemic, the empirical phase in this thesis was completed remotely, resulting in additional considerations of accessibility in a digital world. It embeds concepts of positioning and coproduction, with a focus on autistic teenage girls between 13 and 18 and surfacing their experiences within the complex social discourse. In the social discourse surrounding autism, girls are often missing or misrepresented, for example, in the media and clinical settings. Additionally, misconceptions and stereotypes perpetuate this discourse, allowing little room for alternative perspectives to feature. This thesis seeks to reverse this by enlisting a participatory approach and a coproduction method that makes space for autistic teenage girls' voices, bringing them to the surface.

This study sits on three main thematic pillars; autism and gender, the period of adolescence, and voice and autonomy. Overall, within each phase, the method and data present a novel understanding of the topic area, whilst contributing to wider discourses of participation, expertise, and positioning. The full contributions and applications from the thesis are discussed in more detail in sections 7.4 and 7.5.

### **1.2 Research aims and study phases**

This chapter will present the main research aims of this thesis and outline and provide a definition for the key terminology being discussed within this thesis. In addition, it will provide some background to the development of terms and how they specifically relate to autism.

Whilst each phase included in this thesis utilises specific questions and aims, they were ground within an overarching aim and set of objectives. Each of the studies

brought a unique and different perspective to these, which are discussed in the synthesis of findings in the final chapter. As the thesis was subject to an iterative process (see chapter 3 for further discussion), these aims were developed throughout the entire study period.

The broad aim of this study was to surface the perspectives of autistic teenage girls within the wider social discourse and data currently available. To achieve this aim, five main objectives were identified:

1. To explore how autistic teenage girls are positioned.
2. To identify the topics and concepts of important consideration for this group.
3. To gain an understanding of how autistic teenage girls navigate their social worlds.
4. To engage with stakeholders to support understanding and consider the applications to the wider community.
5. To consolidate understanding by enlisting a participatory approach with key stakeholders.

This is presented through three phases completed: a scoping review, a discourse analysis, and a coproduced empirical phase. The scoping review primarily focused on objectives two and three, the discourse analysis focused upon aim one, and the coproduced phase primarily contributed to objectives four and five. The coproduced phase also contributed to objectives one, two and three, though this was supplementary to the primary objectives.

Figure 1 presents an overview of these studies and displays the change in direction mid-way through. A scoping review aimed to narrow down the focus of the thesis, highlighting the themes in current academic publications to guide the protocol for the exploratory phase. This phase sought to explore how autistic teenage girls experienced their social worlds through interviews and workshops. Ethical approval was achieved for this, however the Covid pandemic paused the project. Whilst initially the data collection was amended to be fully virtual, the unknown timescale and impact

of the pandemic, it was decided that an alternative phase would be used instead. As highlighted in figure 1, this lead back to reviewing the themes from the scoping review, where it was considered appropriate to employ a discourse analysis across two time periods. This further developed understanding of the topic area, with a specific contribution of enhancing the understanding of positioning. The final phase of this study gathered the findings from the first two phases and used them to scaffold the protocol. To limit the possible disruption to data collection due to the pandemic and changing restrictions, a fully online design was enlisted. The main output from this phase was the document produced, with this being shared across Wales with stakeholders as a form of dissemination.

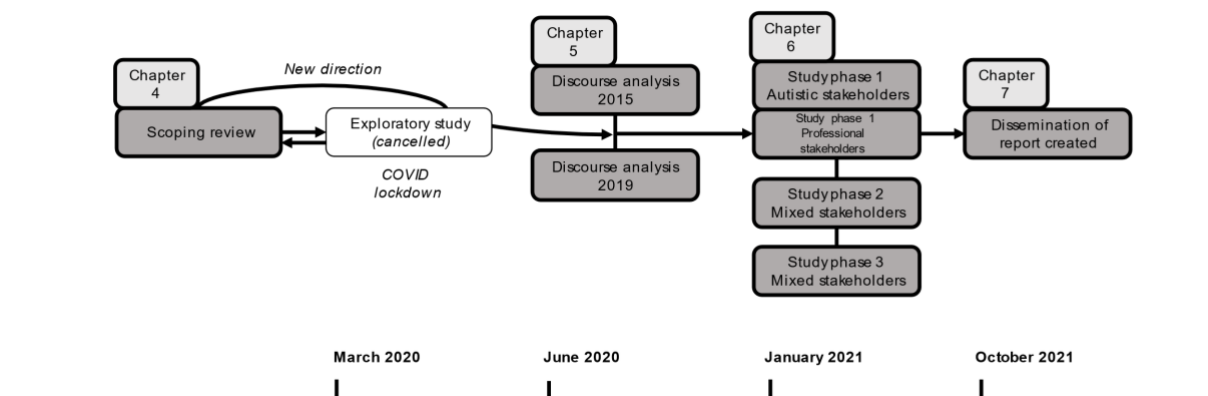


Figure 1: A chronological overview of phases.

### 1.3 Definitions

When describing autism, utilising this language is the preference of the autistic community. To maintain the integrity of this thesis, this was the preferred approach rather than focusing upon terminology that is more prevalent in academic and educational disciplines (APA, 2013). This considered, other lexis, such as Asperger's, ASD and ASC may be used when discussing secondary data sources and stakeholder quotes. In assigning table headings, a key consideration was the role of language in asserting power in the narrative used to describe autistic people. The educational terms and phrases reflect terminology that evolved from diagnostic terms, retaining elements of a medical model of disability. The final column, personal and other terms, was included to ensure that language was considered beyond the medical model to

include the social landscape of discourse. It should be noted that when communicating with autistic people, language should be guided by each individual's preferences to avoid the assertion of power and reflect a person centred approach.

To expand upon the language that features in this thesis, table 1 presents lexis that the researcher came across which have been broadly categorised, for example, diagnostic language. The use of language will be further discussion in chapter two.

<b>Diagnostic terms</b>	<b>Educational terms / phrases</b>	<b>Personal / other terms</b>
Autism Spectrum Disorder Autism Asperger's syndrome Atypical autism Classic autism Kanner autism Pervasive Developmental disorder (PDD) High-functioning autism (HFA) Pathological demand avoidance (PDA) Childhood schizophrenia Childhood Disintegrative Disorder (CDD) Rett Syndrome	Autism Spectrum Conditions On the autism spectrum Autism conditions	Aspie Autie Autist

*Table 1: Terms used to describe autism and their wider categories.*

Autism can be described in a plethora of ways, in turn resulting in disagreement between the autism community and professionals that has presented in print and online networks. Whilst not common practice in academic writing to include such sources, the discussion surrounding language in online networks provides an insight



from autistic stakeholders in a discourse where these voices are traditionally excluded. An example of this is Brown's (2011b) blog that highlights the power of words and language in ascribing meaning and influencing our attitudes. Discussing language goes beyond literal meaning to include the connotations and context of the original phrase, which in turn can result in people becoming insulted and negatively impacted by word choices (Brown, 2011b).

A reason for the range of lexis used to conceptualise and describe autism has been postulated as resulting from the range of ways that autism is positioned in one's life (Kenny *et al.*, 2016). For example, autistic people have a different relationship with language than someone who has encountered it in a workplace or within the community (Kenny *et al.*, 2016). Another influence is the range of language used to conceptualise autism in academic and scientific communities (Kenny *et al.*, 2016). The importance of language is supported by its power to shape people's opinion and reflect the perceptions of autism in society (Kenny *et al.*, 2016).

One of the ways language use has been described is through the term's person-first language and identity-first language. In the field of mental health, person-first language is positioned as reinforcing the recovery model (Jensen *et al.*, 2013). Organisations such as the American Psychological Association (APA, 2009) and United Nations (UN General Assembly, 2007) have adopted this language. On the other hand, identity-first language has been increasingly cited by autistic advocates and literature written by an autistic author (Shakes & Cashin, 2019). For example, Benham (2015) ascribe identity-first language to the neurodiversity movement. The need to identify the terminology that will be used stems from public discussions that demonstrated there was disagreement in the way autism is and should be described (Kenny, Hattersley, Molins, Buckley, Povey & Pellicano, 2016).

#### **1.4 Current thoughts and views of autism in research**

The view of autism in both research and social settings has evolved significantly over the past four decades (Happe & Frith, 2020). In their annual research review, Happe

and Frith (2020) reflect on this, with focus around seven central areas of change, including how each define, operationalise, and recognise autism. Of specific note, in their second area of change which surrounded the prevalence of diagnoses, the likelihood of females being underrepresented was cited (Happe & Frith, 2020). Chapter two provides a synthesis and more detailed exploration of the current research and developments in this field.

It is believed that the first estimate of the prevalence of autism was approximately four in ten thousand (Lotter, 1966). Estimates following the introduction of descriptions of an autism spectrum rose through Wing and Gould's (1979) epidemiological study, to twenty-two in ten thousand. Forty years on, a figure of one in one hundred is widely accepted, with a worldwide median prevalence cited of sixty-two in ten thousand also being cited frequently (Elsabbagh *et al.*, 2012). The past underrepresentation of females in autism research has resulted in several suggestions being made. For example, the importance of including all genders equally within study, as well as exploring the female specific topics that have been previously neglected, such as the experience of adolescence and motherhood (Happe & Frith, 2020).

## **1.5 Situating autism**

Autism has undergone various developments in its understanding and definition over the years, namely because of key diagnostic publications, for example, the Diagnostic and Statistical Manual for Mental Disorders (APA, 1994, 2000, 2013) and the International Classification of Disabilities (World Health Organisation, 2019). The ontological position of autism has evoked much debate, where diagnosis is conceptualised by behavioural markers, with theoretical understandings being predominantly situated in cognitive and psychological paradigms (Milton, 2012). Botha (2021) describes the historical position of autism as within the field of medicine. This position responds to difference negatively as a disorder or disease (Evans, 2013), in turn focusing on preventative measures and cures (Glynne-Owen, 2010).

Autism is conceptualised as a spectrum condition where individuals present differently, therefore, explaining the use of the term in diagnostic labels of ASD and the community

preferred acronym ASC (Dandil *et al.*, 2020; Kenny *et al.*, 2016). This considered, theoretical accounts highlight that this spectrum is underpinned by key features, for example, a cognitive profile of inflexibility and heightened attention to detail (Geurts, De Vries & Van den Bergh, 2014; Westwood, Mandy & Tchanturia, 2017). This was first used within the fifth edition of the DSM (APA, 2013), and encompassed the five diagnoses previous used in the previous edition. These were autistic disorder (299.00), Asperger's disorder (299.80), Rett's disorder (299.80), childhood disintegrative disorder (299.10) and pervasive development disorders not otherwise specified (299.80).

Autism has been defined as 'a lifelong neurodevelopmental condition characterized by differences in reciprocal social interaction, communication, language, and restricted and repetitive behaviours' (Dandil, Smith, Kinnaird, Toloza & Tchanturia, 2020, p.2). The definitions and understandings of autism have developed over the years, from early discussions by Kanner, providing the first description (Kanner, 1943). Through these changes, various terminology to describe the category of difficulties an individual faced have been used, which have varied in their longevity. In the second edition of the DSM (APA, 1968), autism was classified under the umbrella term of childhood schizophrenia as scholars failed to agree on a classification for the children Kanner described in his 1943 paper (Kanner, 1943; Harris, 2018). Following Kolvin's (1971) research developing definitions of schizophrenia and autism, in the third edition of the DSM (APA, 1980), a new category of early infantile autism was created and categorised within pervasive developmental disorders. As a result of the restrictive bounds of this diagnostic label, for example, onset before 30 months of age, revisions were made (DSM III-R) and a new diagnostic label of autistic disorder (Harris, 2018, APA, 1987). The fourth version of the DSM moved to sub-group pervasive development disorders into; autistic disorder, Rett disorder, childhood disintegrative disorder and Asperger Syndrome (Wing, 1981b; APA, 1994). Asperger Syndrome, introduced in 1981, sought to conceptualise the experiences of individuals with social communication difficulties who appeared higher functioning (Harris, 2018). Within the fourth version of the DSM, presenting with no clinically significant general delay in language was a criteria for an Asperger's, rather than Autistic diagnosis. The current edition (DSM V, APA, 2013) utilises the term 'autism spectrum disorder' as a

diagnostic label to include the previous sub-groups. It has been proposed by Harris (2018) that this edition aligns more closely to Kanner's key diagnostic features when considering autistic aloneness and preservation of sameness.

There can be tension around the language used to describe autism, with two key areas that have been identified (Kenny *et al.*, 2016). First, the role of autism in an individual's life and their encounters with it are considered to influence language preferences (Brown, 2011a, 2011b; Durbin-Westby, 2009). For example, some people experience autism personally, others through children and family, whereas some may only come across autism in specific areas of their life, including work, school, and the wider community (Kenny *et al.*, 2016, Snow, 2006). The second area focuses upon how autism is conceptualised within scientific and academic communities (Brown, 2011a; Snow, 2006), as well as the growing presence of neurodiversity movements (Kenny *et al.*, 2016). Both influences acknowledge that language choices have the power to reflect and shape others' opinions about autism, whether this is positive, negative, or indifferent (Kenny *et al.*, 2016; Durbin-Westby, 2009).

The socio-cultural framework of disability (see section 2.7.4.2 for an in-depth discussion) has encouraged language to promote autonomy and a positive identity (Kenny *et al.*, 2016). Efforts to do this initially focused on ensuring language refers to people first as individuals, and their diagnosis only when necessary (Bailey, 1991; Blaska, 1993). This focus was not shared by all campaigners and communities, with those such as the deaf and blind communities explicitly rejecting person-first language (Ladd, 2003; Lane, 2000). Considerations of language use is a longstanding feature in literature, for example, members of the deaf and blind community argue that person-first language seeks to belittle the range experiences and limit possible pride in one's identity (Vaughan, 1993). Discussions about language use draws upon grammatical convention, arguing that person-first language violates the principle that positive pronouns should precede nouns (Vaughan, 1997), with Goffman (1963) arguing that this can enhance the negative portrayal of disability. As a result, language needs to be considered to ensure that it fits with preferences and needs of the group of

individuals being discussed, rather than applying a universal standard (Vaughan, 1993; Zola, 1993).

An alternative approach to language is known as disability or identity-first language, for example, an autistic person (Dekker, 2011). Some individuals consider this to dismiss the claims of negative implications, as it is supported by the grammatical principles of pronouns being placed before nouns (Halmari, 2011). In addition, within the field of autism, community members who view their (or their child's) diagnosis as an accepted part of their identity (Bagatell, 2010), further believe it promoted inclusion within society (Davidson & Henderson, 2010; Hurlburt & Chalmers, 2002). In the wider notion of 'neurodiversity', there is support for identity-first language, as autism is viewed one neurological form within the diversity of the human mind (Nicolaidis, 2012; Robertson, 2010). This movement draws away from the medically driven language such as 'deficit' and 'impairment' and promotes autism as a way of being (Kenny *et al.*, 2016). Baron-Cohen (2000) provides comment on the terms used to describe autism, focusing replacing the potentially disparaging deficit driven lexis with the term 'condition'. Whilst there has been limited research into neurodiversity, the preference for disability-first language is more frequent in those aligned to this movement's beliefs and attitudes (Kapp *et al.*, 2012). This considered, this was not found to have correlations to reducing acknowledgements of deficits in autism (Kapp *et al.*, 2012).

The notion of neurodiversity if not championed by everyone, as individuals and organisations alike want the profound challenges faced by those with autism to go unnoticed or unappreciated (Humphrey & Lewis, 2008). Furthermore, a section of this community use this as support for advocating ways to 'treat' difficulties, and a smaller section continue to pursue prevention methods (Chamak, 2008). This small section of individuals strongly misaligns with the beliefs of the neurodiversity movement (Broderick & Ne'eman, 2008; Chamak, 2008). Whichever view or belief aligns with one's experience, there remains vast and complex differences in the preferences individuals have in the terms used to describe and conceptualise *autism* (Kenny *et al.*, 2016). For those unclear about terminology use, an overriding principle remains to ask those they work with or are describing for their preferences, rather than making

assumptions (Mackleprang, 2010; Mackelprang & Salsgiver, 2009). This demonstrates a person-centred approach, which has positive implications, namely limiting feelings of dismissal or unimportance within decision making processes for individuals with autism and their families (Pellicano *et al.*, 2014a, 2014b; Pellicano & Stears, 2011). For researchers, it is described as an ethical duty to ensure terminology used is comfortable for the community of individuals being represented (Kenny *et al.*, 2016, p.459). Also, clinicians and practitioners should ensure they understand the needs and preferences of individuals, and that they enlist the skills necessary to listen effectively and respond to individuals and their families (Pellicano & Stears, 2011).

### **1.5.1 A critical juncture: The Kenny *et al* (2016) UK study**

Kenny *et al.*, (2016) provided the first large-scale study of UK community members in response to the increasing discussion surrounding language use to describe autism. This study enlisted a wide-ranging sample to explore the perceptions of a range of terminology to describe autism among stakeholder groups using an online questionnaire. These groups included autistic individuals, parents, professionals and families or friends. In total, 4622 responses were received. Following exclusions made, for example, due to not residing in the UK, 3470 responses were included in the analysis. This analysis sought to explore the respondents language preferences and collect any explanations or rationale for these views. Due to the unique nature of this study, it was considered appropriate to include a summary of the key findings in the introduction to this thesis. This was also enhanced due to its location being in the UK and a clear breakdown of participants' demographics being provided.

Many respondents with a diagnosis described language that separates autism from their identity can undermine positive characteristics and reinforce beliefs that autism is a 'wrong' or 'faulty' way of 'being' (Kenny *et al.*, 2016). This finding reiterates previous work which has been conducted (Bagatell, 2010; Davidson & Henderson, 2010), pushing against using person-first language (Hurlburt & Chalmers, 2002). When arguing against this, disability first language was preferred due to the representation of it being part of their identity (Robison, 2011).

Parents who responded varied in the terminology preferred, with some citing autism as a central and positive aspect of their child's and family's identity, a finding previously reported (King *et al.*, 2006). Conversely, some described their child's diagnosis as being distinct from their child (Kenny *et al.*, 2016). Previous literature may provide an explanation as to why opinions diverge, as parents may play multiple roles in their child's life, including caregiving and advocating for their needs (Sousa, 2011; Langan, 2011). Silverman (2011) extend this to include considerations of where the various roles can compete to achieve the desired outcome. An alternative explanation for the variety in parent's language preference is the 'nature of their child's autism' (Kenny *et al.*, 2016, p.458). The reasons for this can vary, though the perception of limiting social stigma may explain the cited preference for receiving an Asperger's diagnosis for their child (Calzada *et al.*, 2012). A previous study in Australia provided support for this through the identification of increased perception of stigma an autism label compared to that of Asperger's (Kite *et al.*, 2013).

## **1.6 Situating concepts**

### **1.6.1 Gender**

As considerations of a specific gender are central within this thesis, exploring its definition and the ways it has been described in the field of autism were considered necessary. Whilst it may have been more appropriate to use the term 'sex' due to its biological grounding, the use of the term gender was used more widely in previous research (e.g., Sedgewick, Leppanen & Tchanturia, 2019; Kirkovski, Enticott & Fitzgerald, 2013). In addition, the term sex was considered to be heavily reflective of the medical model of disability, something that contradicted the epistemological position of this thesis. This term also reflects the role of social norms, roles and expectations that autistic teenage girls may be exposed to, and their influence on shaping development and experiences. Other examples of research include both sex and gender references interchangeably (e.g., Lai *et al.*, 2015). Whilst this thesis will not be looking into gender as a concept, the focus upon the effect of the female gender within autism warrants a definition to be established. For this thesis, the term gender will be used when describing the sex assigned at birth.

Previous research into gender and autism has considered the possible presence of a specific female presentation (Kirkovski, Fitzgerald & Enticott, 2013). Furthermore, the way autism presents in females, otherwise known as the female autism phenotype, has been attributed as a possible reason for the underdiagnosis of females (Hull, Petridis & Mandy, 2020). Whilst similar underlying behaviours are identified, the expression of these is where a female's presentation may differ from traditional autistic behaviours (Hull, Mandy & Petridis, 2017; Lai *et al.*, 2011). An example of this difference is the maintenance of long-term friendships. Whilst similar levels of motivation have been highlighted, autistic females may encounter more challenges than autistic males (Hiller *et al.*, 2014). A more comprehensive synthesis of research can be found in chapter 2 section 2.1. The term 'phenotype' is situated in genetic studies that seek to identify markers for specific conditions, including autism (Losh, Childress, Lam & Piven, 2008). It is noted, however, this thesis adopts the term as relating to the characteristics or manifestations of autism in females, rather than endorsing a genetic exploration.

### **1.6.2 Situating adolescence**

As this thesis is specifically focusing upon the experiences of adolescents, exploring both its definition and wider sociological considerations is important. On a surface level, adolescence is defined as a life period where individual's undergo rapid and complex change (Crosnoe & Johnson, 2011). This life phase encompasses biological changes in puberty (Susman, Dorn & Schiefelbein, 2003), psychological changes and emotional changes (Crosnoe & Johnson, 2011). Focusing upon one's position, during adolescence, the roles of a parent and child may change, with the child seeking more autonomy (Larson *et al.*, 1996). Adolescence has also been described through other terminology, such as teenagers, though the term 'teenager' is conceptualised as being an individual between thirteen and nineteen years of age (Sawyer *et al.*, 2012). Comparatively, adolescence has been described by the World Health Organisation (WHO) as the period between age ten and nineteen (WHO, 2001). Further exploration displays adolescence as a stage of life which individuals go through, and whilst falling under the legal definitions of being a child (UN Convention on the Rights of the Child,



1989), it has been considered as presenting changing dynamics and expectations. Following discussions of adolescence as a life stage, sociological understandings, including the paradigm of childhood, identify adolescence as a transitional period, in which individuals are bridging the gap between childhood, and the independence that adulthood will bring (Zaky, 2016). This is discussed in more detail in the following chapter (2.3).

### **1.6.3 Voice and autonomy**

In traditional views of autonomy, the concept draws on underlying perceptions of one's capacity to make a decision (Kong *et al.*, 2020). In the period of adolescence individuals are moving between the limits and directions given by caregivers, to the self-direction and self-governance associated with the independence of adulthood (Graves & Larkin, 2006). Researchers and research groups are demonstrating a commitment to shift to include children and young people's views through a range of methods, with this being positioned to increase authenticity and reliability (Cocks, 2008; Lewis & Porter, 2004). However, this is often counteracted by budget and time restraints of a project, particularly in groups that present with different requirements, for example, disabled children (Lewis *et al.*, 2008). It is important, therefore, for researchers to acknowledge and be explicit about the reasonable and feasible ways voice features within a project (Lewis, 2010). Also, it should be acknowledged that the value and position of voice in research is influenced by the researcher and individual's views of contributions made, and how they are evaluated, which Komulainen (2007) considers reflective of voice being a social construction.

Freire (2000) adds that encouraging voice requires partners to be viewed as equals, where each has a valuable contribution. This is in comparison to viewing one individual as expert. Derezotes, Ashton and Hoffman (2004) have described voice as a power of expression that can include words and actions, that can be interpreted to have different meanings. These interpretations can be influenced by the setting and context of the interaction (Belenky, Clinch, Goldberger & Tarule, 1996). Definitions of active voice focus on individuals' contributions being valued, and to be true of their own experiences of the world around them, requiring researchers to ensure interpretations

are correct (Fane *et al.*, 2018). Conversely, passive voice adopts a somewhat tokenistic value attached to the experiences, for example, viewing adolescents as not yet being able to fully understand the world around them, thus placing lower value on views and opinions (Grover, 2004). Research on the period of adolescence has highlighted the role of voice in promoting positive interactions, with a specific focus on receiving health care (Jolly, Weiss & Leih, 2007).

## **1.7 Structure of thesis**

This thesis includes eight chapters, including (1) introduction, (2) literature review, (3) approach to research, (4) scoping review, (5) discourse analysis, (6) empirical phase and (7) discussion.

Chapter One situated the thesis, its aims, and the objectives which it sets out to meet. In addition, this chapter brings together some of the key concepts within autism, as well as the wider field of disability. It also demonstrates the specific meaning and value of the terms within this thesis. These definitions will be adopted through the critical discussions within the literature review, as well as throughout the empirical studies conducted as part of the thesis. Whilst a relatively short summary of the terms and their development, they are enough to show the researcher's position. An in-depth exploration would have been beyond the scope and purpose of the chapter.

Chapter Two will consider previous literature in more depth, drawing comparisons to board concepts, such as disability, and examples of the use of research in fields of Dyslexia to inform research design. The definition of the social world will be discussed, with a consideration of the topics falling within this. Overall, it demonstrates areas which can be used to inform this thesis, as well as identifying the gaps and cautions needed when applying the knowledge gained. This provided an appreciation of the scope of the topic area, guiding the researchers focus on the subsequent phases.

Chapter Three primarily serves to explore the position of this thesis in the wider body of research. Specific focus is given to the epistemology and ontology of this thesis, which includes the pathway of developing knowledge to establish a worldview. Several approaches and positions will be described and be consolidated to focus upon those selected to meet the objectives of the thesis.

Chapter Four presents a scoping review which is guided by the initial narrative literature review identified in Chapter Two. The secondary data analysis method presents a clear systematic pathway to explore previous literature and refine the research questions. The scoping review enlisted a thematic analysis to draw themes apparent from the review.

Chapter Five details a phase utilising secondary data, adopting the conventions and methods ascribed with a Foucauldian discourse analysis. This focused on the portrayals of autistic females in online news media across two time points. This provided an alternative output to the scoping review that involves different actors and viewers of the knowledge produced.

Chapter Six presents a discussion of the empirical phase co-produced with stakeholders. It utilises online workshops to engage over several months with these collaborators to generate 'data' in the form of a report. This chapter discusses the design of the study and analysis undertaken, focusing upon the knowledge gained through the data generated, rather than singularly presenting a narrative of the data.

Chapter Seven draws upon the findings of the elements of the thesis, discussing the overall themes, and reflecting upon the aims set out by the researcher. Through this, the strengths of the approach are discussed, as well as the limitations. After the narrowing of focus throughout the thesis, this chapter widens its focus, specifically on the implications of the thesis findings and areas which may benefit from further

research. Finally, this chapter will provide an autobiographical reflection on the completion of this thesis.

### **1.8 Summary of chapter**

This chapter situates the unique contribution of this thesis and highlights the central concepts and their definitions. Through this, the aims and objectives of this study are presented, linking to the other chapters within this thesis, or, as they are otherwise known, the different phases of the study. This provides a contextual overview of the topic area, the study processes, and its position in the wider research network.

## **Chapter 2: Locating Autism within the Literature and mapping key frameworks and concepts: A narrative review**

### **2.1 Introduction to the chapter**

The purpose of this chapter is to provide a narrative review of the research in autism, specifically focusing upon female adolescents and their social experiences. The aim of this is to identify relevant literature, frameworks and concepts to establish the research area this study is positioned within. Within the complex social discourse of autism, research is a central source of information and therefore an important consideration in study development. In addition, this chapter will consider the key approaches and concepts identified within the evidence base, including peer relationships, social participation, and the difficulties and challenges experienced by autistic female adolescents. The findings from this review identify a series of themes that reflect the complexity and multi-disciplinary nature of the study of autism, specifically in the targeted population. Through the evaluation of these themes and the related previous research, applications and considerations for the current studies will be extracted. Overall, this chapter aims to add to and expand upon the definitions, concepts and theoretical perspectives discussed in the introductory chapter, and to surface relevant conceptual frameworks, specifically, considering their influence on the current thesis.

### **Scope and methods**

Through the chapter, concepts stemming from education, psychology, sociology, and numerous other disciplines will be explored, presenting a multidisciplinary focus. In addition to these, consideration of the field of research will feature, as well as directions towards future participatory research. Reference will be made to some of the legal frameworks and developments which require consideration, specifically in understanding the background of the topic, as well as their influence on the appraisal of literature. In line conducting a narrative review, there were no bounds placed upon the time span of the literature to be included.

## **2.2 Previous research**

### **2.2.1 Gender and previous research with females**

Reference to the influence of gender in studies considering autism and symptom expression have been made, however, it has been claimed that this research is limited as it lacks findings from real-life clinical settings and gender is rarely the primary consideration (Baron-Cohen *et al.*, 2011; Fulton *et al.*, 2017; Lai *et al.*, 2013; Sipes *et al.*, 2011). Due to the challenges in the identification of autism in females (Gould & Ashton-Smith, 2011; Shattuck *et al.*, 2009), as well as the relative absence of females in investigatory studies (Lai *et al.*, 2015), the difficulties for this group in obtaining a diagnosis and support are unsurprising (Constantino & Charman, 2012; Fountain *et al.*, 2011). There is also evidence suggesting that there are negative implications of not receiving or having a delay before receiving appropriate support and diagnosis (Kopp & Gillberg, 2011; Kopp *et al.*, 2010; Lai *et al.*, 2014; Werling & Geschwind, 2013). These negative implications are broad, and may span across an individual's life and development, as well as their well-being and mental health (Kopp & Gillberg, 2011; Kopp *et al.*, 2010; Lai *et al.*, 2014; Werling & Geschwind, 2013). Some of these negatives may include, for example, social exclusion and social isolation (Baldwin & Costley, 2016; Bargiela *et al.*, 2016; Haney, 2016).

Whilst females have been included in some mixed-sex samples, the lack of fully female samples prevents the exploration of female specific issues (Nichols & Blakeley-Smith, 2010; Stokes & Kaur, 2005), and many commentators have called for this to be addressed (Hsiao *et al.*, 2013; Nichols *et al.*, 2009). This is important, as studies suggest that overall social abilities are higher in autistic females (Solomon *et al.*, 2012; Nichols *et al.*, 2009; Baron-Cohen *et al.*, 2011; Rivet & Matson, 2011b). In addition, behavioural difficulties, such as inappropriate play conduct, have been shown to be higher in males than in females (Lai *et al.*, 2011; William *et al.*, 2012). This may be considered to provide further justification for exploring females' experiences.

The association between adolescence and changes in the complexities and frequencies of social interaction and communication, is not singularly found in studies of autistic individuals (Card *et al.*, 2008). However, for autistic females, this may be

increasingly challenging due to the need for time to process and formulate responses to the increasingly fast paced and complex communications (Nichols *et al.*, 2009). The focus upon the period of adolescence is supported by research finding that social and inter-personal relationships become more problematic to manage within adolescence (Bauminger *et al.*, 2008; Carrington *et al.*, 2003). In addition, it has been postulated that a factor is the lack of success the compensatory and coping methods used in early childhood have during adolescence (Cridland *et al.*, 2014). Links with individuals experiencing mental health difficulties alongside autism have also been considered within the specific domain of friendships, specifically in the perceived success and inclusion within them (Muller *et al.*, 2008).

Navigating the complexities of the social world may result in secondary effects for individuals, specifically, from the strategies, methods and compensatory mechanisms employed. For example, it may be suggested that such behaviours are related to the higher rates diagnoses of mental illness' made for autistic females (Chan & John, 2012; Cottenceau *et al.*, 2012; Rivet & Matson, 2011a; Seltzer *et al.*, 2004; Solomon *et al.*, 2012; William *et al.*, 2012). A more in-depth synthesis of the social world is presented in section 2.3.2.

### **2.2.2 Consideration of females in autism research**

Whilst research has been growing in the field of autism generally, the attention given to females with a diagnosis has only recently started to increase, as previously, the identified prevalence in males also featured among research (McPartland & Volkmar, 2013). An even smaller amount of research considers female individuals who appear to be cognitively able, as well as those whose presentation does not match the usual presentation (Lai *et al.*, 2011). In relation to the presentation and perceived difficulties in autistic females, the phenotype has, by some, been identified as different to that of males (Nichols, Moravcik, & Tetenbaum, 2009; Kopp, Kelly & Gillberg, 2010; Gould & Ashton-Smith, 2011). This considered, Tierney, Burns and Kilbey (2016) consider the conceptualisation of the female phenotype to be undetermined compared to males (see section 1.2.5).

Utilising a standardised classification system for diagnosis, such as the DSM (APA, 1994; 2000; 2013), is considered to enhance communication and consistency among professionals nationally and internationally, specifically, diagnoses facilitate the implementation of support (Valkmar & McPartland, 2014). However, such diagnostic systems are said to face challenges with certain demographic profiles, for example, gender, age, and developmental level (Valkmar & McPartland, 2014). It is interesting to note that new editions of the DSM being published elicited consideration of whether individuals diagnosed under DSM IV (APA, 1994; 2000), would still be given a diagnosis under DSM V (APA, 2013; Matson *et al.*, 2012; Matson, Hattier & William, 2012; Mattila *et al.*, 2011; Wilson *et al.*, 2013). Whilst an in-depth consideration and analysis of the evolving diagnostic criteria would not be appropriate for this thesis, consideration should be made of Frazier *et al.*'s (2012) findings. These utilised a national registry as part of a large study and found that the inconsistencies of diagnosis from DSM IV and DSM V was most pronounced in females (Frazier *et al.*, 2012).

Each revision of the diagnostic criteria has consistently aimed to increase the accuracy and consistency of diagnoses (Kopp & Gilberg, 2011; Lord *et al.*, 2012; Williams *et al.*, 2008), however, the under identification or misdiagnosis of females persists still (May *et al.*, 2017; Shattuck *et al.*, 2009). This has been argued to support the need for current population research to be conducted (APA, 2013; May *et al.*, 2017).

In addition to considerations of standardised criteria, research and clinical practice lacking in female representation may have moulded a male-biased understanding of autism (Lai *et al.*, 2015; Baron-Cohen *et al.*, 2011). With the two most widely utilised classification tools being based on Kanner and Asperger's descriptions of autism, they are likely to be sensitive to the male presentation (Gould & Ashton-Smith, 2011). This understanding also includes clinical diagnostic tools, for example, the ADI-R and ADOS, with the validation of these not accounting for sex differences (Lord, Rutter & Couteur, 1994). Studies such as Mussey, Ginn and Klinger (2017) and Beggiato *et al.*, (2017) explored the sensitivity to sex in these tools, with findings of a lower sensitivity of identification of autism in females. Resulting from these findings of lower sensitivity



are questions about the reliability of these tools (Kopp & Gillberg, 1992; Pilowsky, Yirmiya, Shulman & Dover, 1998; Young, Oreve & Speranza, 2018).

The concept of male bias has not only been discussed recently (Baron-Cohen *et al.*, 2011), it has previously been discussed over thirty years ago (Tsai, Stewart & August, 1981; Lord, Schopler & Revicki, 1982; Wing, 1981a; 1984). Whilst at initial thought, this would appear positive that it has been considered for a long time, it conversely can be viewed as being lacking if there is still the need for additional consideration over thirty years from the first discussions. This could also be interpreted to show that the current and ongoing approaches do not appear able to facilitate the required improvements.

To conclude this section, two main suggestions of actions to address this are presented. First, developing new diagnostic criteria that addresses sex differences and is sensitive to them may be necessary (Duvekot *et al.*, 2017; Lai *et al.*, 2015). The second focuses more broadly on understanding of autism presentation, positioning the exploration of symptoms not the measurement of them as the barrier to appropriate diagnosis of females (Frazier & Hardan, 2017; Werling 2016). This includes a better understanding of the range of behaviours that may present, utilising previously identified themes of behaviours in autistic women and girls (Frazier & Hardan, 2017; Werling, 2016).

#### **2.2.2.1 Lai *et al.*'s 4-level conceptual framework**

Lai *et al.* (2015) specifically explored sex and gender differences in autism through a review of previous literature. As a result of which, a four-level conceptual framework was designed to guide future research as well as summarise previous findings. This is especially useful in identifying questions which need to be asked when using this framework in the more specific field of the social world. For the purposes of this thesis, more specific focus will be directed towards levels one and two, as these are more closely linked to the research questions. As a result of co-occurring conditions being

noted in some autistic individuals, this framework may provide guidance in how these should be considered alongside that of autism (Gillberg, 2010).

Level 1	Nosological and Diagnostic Challenges
	<ul style="list-style-type: none"> <li>• Qualitative differences between males and females with autism</li> <li>• Quantitative differences in the normative distribution of autistic traits between males and females</li> <li>• Developmental differences between males and females with autism</li> <li>• Factors associated with under-and/or misidentification of females with autism</li> </ul>
Level 2	Sex/Gender-Independent and Sex/Gender Dependent Characteristics
	<ul style="list-style-type: none"> <li>• Behavioural features, Co-occurring conditions, Cognition, Growth trajectories, Anatomy, Physiology, and Biology, Genetics</li> <li>• Similarities and differences between males and females with autism</li> <li>• Understanding how the findings are influenced by intellectual level and co-occurring conditions</li> </ul>
Level 3	General Models of Etiology: Liability and Threshold
	<ul style="list-style-type: none"> <li>• Clarifying sex/gender-differential etiological load, threshold, and genetic heterogeneity.</li> <li>• Testing sex/gender-differential shifts of liability distribution</li> </ul>
Level 4	Specific Etiological-Developmental Mechanisms
	<ul style="list-style-type: none"> <li>• Whether normative sex differences in genetic, epigenetic, and pre-/perinatal environmental factors contribute to autism etiologies.</li> <li>• Whether gendered socio-cultural factors contribute to the emergence, lifespan development, and identification of autism.</li> <li>• Moderating effects of sex/gender in etiologies.</li> </ul>

*Table 2: A summary of Lai et al's (2015, p.19) 4 stage framework and key topics*

### *Framework Level 1*

Through considering qualitative differences between males and females, it has been reported that a female presentation or phenotype may be identified (Gould & Ashton-Smith, 2011; Kopp & Gillberg, 2011; Attwood, 2007). These findings may have been influenced by the standardised measurement tools, for example the Autism Diagnostic Observation Schedule (ADOS, Van Wijngaarden-Cremers *et al.*, 2014), as it was constructed and validated through predominantly male identified cases (Rutter, Caspi & Moffitt, 2003; Kreiser & White, 2014).

Quantitative considerations appear to demonstrate a normative distribution of traits across males and females (Constantino, 2011; Baron-Cohen *et al.*, 2001), however, enlisting universal gender norming, like that in some fields of medicine, should consider possible bias, as well as diagnoses being unable to be solely reliant on statistical findings and significance (Lai *et al.*, 2015). This is highlighted through research into gender in society that shows how females are encouraged to display a higher number and level of social behaviours than males (Bruyn & Cillessen, 2008).

Diagnostic challenges may be somewhat influenced through the nosological issues identified previously, as well as issues of gender bias in the interpretation of behaviours and challenges (Kreiser & White, 2014; Goldman, 2014).

### *Framework Level 2*

This level considers various findings surrounding the experiences of females compared to males. For example, when comparable childhood autistic symptoms and current cognition ability is controlled, females show less evident autistic behaviour when in interpersonal contexts (Lai *et al.*, 2011). Comparisons of externalising and internalising behaviours in autistic samples demonstrate females as having higher levels of internalising and social symptoms than males, who demonstrate higher externalising behaviours (May, Cornish & Rinehart, 2014; Hiller, Young & Weber, 2014; Solomon *et al.*, 2012; Hottman, Bolte & Poustka, 2007). These differences may

be more pronounced and have a more significant distinction in individuals who would have previously been considered 'high functioning' (Lai *et al.*, 2013).

### **2.2.3 Age considerations in research**

Whilst adolescence has not been explicitly studied in previous publications, findings from those which consider age alongside symptomology and difficulty may provide direction. Interestingly, Schopler *et al.*, (2010) found a negative correlation between age and autism symptomology and difficulties, namely that increasing age is correlated to a reduction in these characteristics. Furthermore, this has been extended through longitudinal studies reporting improvement in social interaction, emotion regulation and empathy (McGovern & Sigman, 2005). These findings could provide a model in which to consider areas of interest specific to this study, for example, social navigation.

Difficulties with executive functioning, sometimes described as executive dysfunction, is frequently linked with autism (Hill, 2004; Kenworthy *et al.*, 2008). Executive functioning can be defined as the processes involved with controlling, directing, or coordinating other cognitive processes, for example, attention and planning (Lee, Bull & Ho, 2013). In comparison to the findings above, studies in this field yield contrasting results linked with increasing age. For example, studies of working memory appear to progress consistently from the early years, through school age and into adolescence (Conklin *et al.*, 2007). Additionally, the rapid improvement of inhibition in early childhood is not consistent, and slows throughout adolescence (Best & Miller, 2010). As demonstrated through the two areas above, it is noted that not all areas of development will follow a linear trajectory throughout development. In addition, there have been links made between these difficulties and having a greater number of autism symptoms (Yerys *et al.*, 2009; Kenworthy *et al.*, 2009). Whilst informative, an in-depth discussion and evaluation of this specific area is beyond the scope of current study.

Within the body of research focused upon age, it has been identified that the transition from childhood to adolescence and adulthood is an area that has received a limited consideration (Kozlowski *et al.*, 2012). Further, this transition has been described as one of the most challenging experiences young people with additional needs face (Pallisera, Fullana, Puyalto & Vila, 2016). Adolescence translates childhood experiences and abilities into those required for adulthood, with status and competency in social settings being valued (Johnson, Crosnoe & Elder, 2011; Steinberg & Morris, 2000). This considered, the views of individuals experiencing this transition have been sparse in literature (Cavet & Sloper, 2004; Kumbhani & Wirz, 2009; Mill, Mayes, & McConnell, 2010).

Furthermore, adding the variable of gender to such exploration has primarily been limited to samples and challenges in the early years (Sipes *et al.*, 2011). The definition of the early years within autism focuses typically on individuals between birth and eleven years, and therefore focuses upon transitions from pre-school to full time education, or primary to secondary education (McIntyre, Blacher & Baker, 2006). Though, the citing of early years can be more specific and narrowed to pre-school years (from birth to aged 3), especially when considering the effect of gender on the symptomology and presentation which may be indicative of autism (Andersson, Gillberg & Miniscalco, 2013).

#### **2.2.4 Female phenotype**

The specific focus on females is supported by an awareness that the female phenotype and thus presentation of autism in this group may be different to that in males (Nichols, Moravcik & Tetenbaum, 2009; Kopp, Kelly & Gillberg, 2010). Furthermore, Gould and Ashton-Smith (2011) recognise that gender differences may also be applicable to the needs of autistic individuals. Lai *et al.*, (2015) recognise the early stage of this area of research and the lack of a definitive account of the female phenotype. The lack of awareness and clarity of what a female profile may look is not surprising, with the lack of research investigating gender differences being a central consideration (Mandy *et al.*, 2012). In an unusually large sample (100 participants), Dean *et al.*, (2014) surmised that the key differences in phenotypes for males and

females were a result of the differing manifestations of concepts, for example, social exclusion.

The presence of a specific female phenotype has been cited as an explanation for the ascertainment bias for autistic females (Tierney, Burns & Kilbey, 2016). Diagnostic criteria and scholars alike have attempted to conceptualise the female phenotype. These cite how female-specific presentations of strengths and difficulties encounter difficulties when they deviate from the male-based conceptualisations of autism (APA, 2013; Hiller *et al.*, 2014; Lai *et al.*, 2015; Mandy *et al.*, 2012). In addition, compensatory masking or camouflaging techniques used to hide difficulties have been cited as a feature of the female phenotype (Kenyon, 2014). This still has room for clarity, specifically in the need for a conceptual definition of camouflaging and measurement tools with high validity and reliability to be developed to assist quantitative enquiry (Bargelia, Steward & Mandy, 2016). The female phenotype cited has been discussed in depth by Lehnhardt *et al.*, (2016), with specific focus upon gender differences identified in several areas, for example restricted and repetitive interests (Mandy *et al.*, 2012; Van Winjngaarden-Cremers *et al.*, 2014), and their relevance when attempting to define the phenotype. Whilst there is yet to be an agreed definition of the female phenotype for autism, the awareness of the need for it to be distinguished is frequently cited (Lehnhardt *et al.*, 2016).

### **2.2.5 Missed or misdiagnosis**

Whilst research relating to diagnosis is limited (Aggawal & Angus, 2015), longitudinal population studies recognise how understandings of camouflaging, along with more sensitive tools, have contributed to better recognition and assessment of females (Jensen, Steinhausen & Lauritsen, 2014; Kocovska *et al.*, 2012). Camouflaging is described as acting in a way which is considered neurotypical or 'normal' (Lai *et al.*, 2019). Furthermore, there are considered three areas of camouflaging, the first being masking, the second enlisting compensatory mechanisms and third assimilation (Bargiela *et al.*, 2016; Lai *et al.*, 2019). This may include hiding and trying to control behaviours considered to be associated with autism, for example difficulties with eye

contact, as well as scripting and replaying successful social interactions (Hull *et al.*, 2017; Lai *et al.*, 2019).

Camouflaging, and other compensatory mechanisms have been said to limit the identification of difficulties, as well increasing difficulties in implementing timely and appropriate support (Jensen, Steinhausen, & Lauritsen, 2014; Kocovska *et al.*, 2012). The concern regarding the misdiagnosis or missed diagnosis of autistic females is enhanced because of camouflaging (Rynkiewicz *et al.*, 2016). The impacts of behaviours observed by clinicians and schoolteachers may result in this, as far fewer reports of social difficulties and issues surrounding friendship and behaviour were reported in female samples (Hiller, Young & Weber, 2014).

When considering cases of missed diagnosis, some are missed during childhood, whilst others may be referred to mental health services for treatment of a psychiatric condition, often during adolescence (Aggarwal & Angus, 2015). Links between autism and the need for psychiatric intervention have been considered, with some findings suggesting those with autism identified in childhood, and those with autistic traits, were at an increased likelihood of psychotic experiences during adolescence (Sullivan *et al.*, 2013). Whilst the focus is not upon the comorbidity aspect, the possibility for misdiagnosis is again reinforced, as well as adolescence being considered a critical period of development (Aggarwal & Angus, 2015, Sullivan *et al.*, 2013). An additional possible factor influencing the missed or misdiagnosis of females may be cognitive and language abilities of individuals (Mandell, Novak & Zubritsky, 2005). This was demonstrated in Aggarwal and Angus' (2015) study in Australia, who found the absence of significant cognitive, or language deficits contributed towards the delay in samples receiving a diagnosis. Mandell, Novak and Zubritsky (2005) reinforce this in their identification that individuals with one, or both deficits resulted in an earlier autism diagnosis.

## **2.3 Key topics**

### **2.3.1 Adolescence**

The changes and challenges in the period of adolescence and early adulthood are not a recent consideration, with research in the 1970s documenting the increasing interest in social interactions and relationships for autistic individuals (Kanner, Rodriguez, & Ashenden, 1972; Schopler & Mesibov, 1983). In addition, the importance of ‘fitting in’ with social norms and having the perceived positive experiences witnessed in peer groups has been shown to be heightened during this period (Tse *et al.*, 2007). Adolescence presents changing social and behavioural expectations which are intensified as the nature and meaning of this period continue to evolve (Settersten, Fursteberg & Rumbaut, 2005).

Specific focus on adolescence stems from understandings that during this stage of life, social dynamics increasingly change, and social interactions and relationships become more complex (Seifert, Hoffnung & Hoffnung, 2000). These changes and increasing complexities in various aspects of an individual’s social world are considered more so in female populations (Foggo & Webster, 2017). Therefore, autistic individuals, particularly those who are female, may be additionally challenged to change and adapt the way they navigate social rules and dynamics (Landa & Goldberg, 2005).

As an effect of these growing complexities, social relationships with others have an increasingly important role (Brown & Klute, 2003; Masten *et al.*, 2012). These relationships are considered a protective factor for instances of negative well-being and mental health difficulties in adolescent females (Mazurek & Kanne, 2010; Waldrip, Malcolm & Jensen-Campbell, 2008). Social interactions and friendships are areas where autistic females may have different experiences and challenges than males (Mandy *et al.*, 2012; Sedgewick *et al.*, 2015). However, this area remains scarcely researched, with those enlisting the opinions and experiences of adolescent females through first-hand accounts being fewer still (Foggo & Webster, 2017).



### **2.3.1.1 Sociology of childhood**

Now over twenty years old, the 'new' sociology of childhood still perpetuates the research agenda when involving children and young people. This time period has witnessed a cross-disciplinary increase in research that encompasses first-hand experiences and views of the world (Brady, Lowe & Lauritzen, 2015). The sociology of childhood emerged as a challenge to notions of children being viewed as passive objects that were vulnerable as they were not yet 'adult' (James & Prout, 1997; Qvortrup, 1994). In comparison, this shift viewed children and young people as possessing agency and actors in their social worlds (James, Jenks & Prout, 1998). Overall, the life-stage of childhood and adolescence was established, underlined by understandings of the rights attributed to this group of people (Alanen & Mayall, 2001).

The sociology of childhood has presented various approaches to childhood, crossing various disciplines. In the field of autism, links with developmental psychologies top-down approach have been identified. This approach is considered to have produced the universal childhood, in which others can be measured, assessed, and compared to this, with deviations considered to be problematic (Leonard, 2016). Specifically, understandings of normality produced by the construction of a universal child has been critically evaluated, for example in fields of additional needs (Leonard, 2016). Post *et al.*, (2013) present a simple view of a top-down versus a bottom-up approach in the context of understanding the needs of autistic people. Specifically, they position 'top-down' to involve the transference of professional expertise onto autistic people and support they are given, with a bottom-up approach being positioned as the opposite. This approach focuses on autistic voices and their families, being considered experts by experience, which in turn inform professional practice (Post *et al.*, 2013).

The universality of childhood has been argued by anthropologists as being a concept which needs to be resisted, as they are not considered to represent diversity within society (Bluebond-Langer & Korbin, 2007). In relation to the social and environmental experiences of autistic adolescents the need for individual consideration that represents diversity is supported (Plomin & Daniels, 2011). The blurring of boundaries between childhood and adulthood have been discussed, which is considered to

support the focus on adolescence as a bridge between these two states (Leonard, 2016; Prout, 2005). Valentine (2003, p.41) similarly discusses this, enlisting the term 'youth' as a category of individuals, during which, they describe this as bridging the "perceived status of dependent childhood and independent adulthood". The epistemological interest in including children within research stems from the difference between viewing children as subjects of research, and research objects (Wyness, 2012). Furthermore, this interest portrays children's subjective worlds as being worthy of research in their own right (Wyness, 2012).

This sociology of childhood presents an appreciation for the group of autistic teenage girls in a wider socio-cultural network that is likely to influence research participation, clinical practice and how they are viewed in society.

#### **2.3.1.2 Agency and voice**

Following on from the sociology of childhood, one of the aspects of the new paradigm considered within this study is the acknowledgement of children's agency and voice (Qvortrup, 2009, p.4-6). This aspect is supported by the aim of investigating experiences and strategies employed to navigate the social world, through first-hand accounts. Furthermore, concepts of individuals having agency and the ability to have a voice in matters that concern them, is representative of understandings that they have capacity to act independently (James & James, 2012). Such agency is considered to support the inclusion of children and young people in research that concerns them, specifically in that if they are agents, they have a right to be included (Valentine, 2011). Furthermore, Ridge (2006) extend this view of participation to it being a fundamental principle of social inclusion. The extent to which this participation is undertaken can vary, with Sinclair (2004) describing four key elements: the level of participation, the focus of decision-making, the type of activity, and the age/ability of child/young person taking part.

The use of methodological approaches that allow for children and young people to contribute to research can help to challenge the assumptions and perceptions of such

individuals not having the competency to contribute as both decision makers, contributors, and active citizens (Aldridge, 2012). Furthermore, when including these participants, ensuring that they exercise ‘some agency and control...’ in if and how they participate, is considered to contribute to active inclusion in topics for which their participation previously may not have been considered (Thomson, 2008, p.5). Whilst participation may not result in direct benefits for individuals, there may be indirect benefits through using collaborative and qualitative approaches, for example, satisfaction of being listened to (McDonald *et al.*, 2013). These indirect benefits are often more valued in vulnerable populations due to the infrequency of other social engagement opportunities (Finnegan & O’Donoghue, 2017).

### **2.3.2 Social world in adolescence**

The heterogeneity and the perceived severity of challenges is considered to have inhibited the progress of understandings and awareness’ of autism (Pelphrey *et al.*, 2011). Specific variability between individuals can be related to social domains, for example, whilst for some there could be a near absence of interaction and the desire to do so, others may exhibit more subtle challenges and appear to manage social interactions (Pelphrey *et al.*, 2011). Whilst presenting in a source distanced from the field of autism or inclusion, Denscombe’s (2014) citation of the social world being complex and compiling of numerous layers to be considered demonstrates its thought in wider fields of research. Behaviours associated with relational aggression, including rumour spreading and social exclusion, are more commonly used in typically developing females than typically developing males (Archer, 2004; Archer & Coyne, 2005; McVey *et al.*, 2017). For autistic females, challenges in understanding functions of social interaction, such as relational aggression, may result in difficulties in developing and maintaining friendships with typically developing peers (McVey *et al.*, 2017). Further, because of such negative experiences and the fear of rejection, these individuals may be more likely to withdraw from social interaction (Bellini, 2006).

In addition to social interaction, social perception presents additional complexities to day-to-day life. Social perception can be explained as an evaluation of those around us, their intentions, and possible dispositions, with gaze, body movement, hand

gestures and facial expression being cues to aid this evaluation (Allison, Puce & McCarthy, 2000). Whilst a dated source, this definition has continued to be used and cited within more recent works (for example, Pelphrey *et al.*, 2011), and it also presents a clear definition to be utilised.

Whilst the social world has been a more recent development, the awareness of social challenges has long predated this thesis, namely through the coined label ‘the social brain’ (Brothers, 1990). Despite the neurological basis of this theory, along with the reliance on brain imaging, it still reinforces that social experiences for autistic individuals require consideration (Frith, 2007).

The conceptual understanding of the social world has been influenced by the increasing use of online communications through social networking sites (Ahn, 2010). Developing relationships and interacting with others can occur in face to face or online settings, with the similarities and differences between these at times being unclear (Xie, 2007). The use of social network sites has been suggested to encourage relationship development, with an increase of social capital being a likely result (Ahn, 2010).

Research specifically focused upon the link between social network use and social capital identified higher social capital in individuals using social networks (Ellison, Steinfield, & Lampe, 2007; Valenzuela, Park, & Kee, 2009). Previous research has found increased feelings of being connected to the world in teenagers engaging with social networks (Donnath & Boyd, 2004; Williams, 2006). This may provide applications to autistic adolescents, as the challenges associated with face-to-face communication are likely to be reduced using these platforms, whilst social capital remaining in line with peers.

### 2.3.4 Camouflaging

Camouflaging is considered a strategy mainly employed in social situations, focused on disguising, and compensating for difficulties of deficits (Hull *et al.*, 2017; Robinson *et al.*, 2020). Autistic individuals in addition to clinicians have described this strategy for several years (Lai, Baron-Cohen & Buxbaum, 2015), with recent times witnessing an increase in investigations and explorations (Cage & Troxell-Whitman, 2019; Hull *et al.*, 2017, 2018; Lai *et al.*, 2017). Three components of camouflaging have been identified, including masking, compensation, and assimilation (Robinson *et al.*, 2020). Masking focuses upon hiding characteristics or traits of autism, presenting alternative personas that are perceived to be desirable (Cage & Troxell-Whitman, 2019). Compensation involves developing ways to overcome the innate difficulties autistic individuals may experience, with many using alternative methods than individuals without autism (Livingston & Happe, 2017). Finally, assimilation describes the efforts to fit in with others and perceived norms and societal expectations (Hull *et al.*, 2018).

A limited body of research has considered camouflaging within neuro-typical samples, with findings indicating a theoretical relationship with reputation management (Izuma, Matsumoto, Camerer & Adolphs, 2011). Wider descriptions of this, for example using terms of self-presentation, involve motivations to build public reputation, which may differ to private impressions of abilities (Leary & Kowalski, 1990). This considered, research by Cage, Pellicano, Shah and Bird (2013) identify that these strategies are used less often, and to a lesser degree in samples of autistic individuals. This does not however negate the higher levels of camouflaging in samples of autistic individuals compared to those without (Hull *et al.*, 2018).

The heterogeneous nature of developmental trajectories for autistic individuals are widely acknowledged, though there is a limited understanding of the reasons for this (Howlin & Magiati, 2017). Specifically, it remains unclear how and why some individuals can demonstrate a neurotypical behavioural presentation when they experience difficulties or differences in areas of cognition (Livingston, Carr & Shah, 2019). Various explanations have been proposed to explain this, with a prominent focus upon the role of compensation to detract from areas of diversions from what is

considered the norm (Livingston & Happe, 2017). This is described as using alternative cognitive routes to present 'neurotypical behaviour', thus attempting to not draw attention or suspicion (Livingston, Shah & Happe, 2019, p.766). Investigations have generally focused upon social domains, though, non-social difficulties may also enlist similar strategies to compensate for difficulties, for example, in education settings (Livingston, Shah & Happe, 2019). Other adaptive strategies recognised include resilience, which focus upon avoiding negative outcomes despite exposure to the area of challenge (Lai & Szatmari, 2019; Rutter, 2013). However, adaptive strategies within autism are not responding to risk, and the challenge remains on a cognitive level despite an apparent lack of observable difficulties (Livingston, Shah & Happe, 2019). The impact of these adaptive strategies may include challenges in identifying the need for and nature of support an individual could benefit from (McPartland, 2019). Individuals who have a history or evidence of enlisting such strategies have been found to receive diagnoses later in life or may not receive one at all (Bargelia, Stewart & Mandy, 2016; Lai & Baron-Cohen, 2015). Linking to the focus of this thesis, this area of difficulty is cited as more acutely prevalent in females, in addition to this group already being less likely to receive a diagnosis (Bargelia, Stewart & Mandy, 2016; Lehnhardt *et al.*, 2016; Ratto *et al.*, 2018). Once receiving a diagnosis, the impacts of compensation remain influential, for example, support needs being underestimated or dismissed as the need is not obvious (Livingston, Shah & Happe, 2019).

The concept of compensatory strategies, specifically camouflaging, have featured in a small, but increasingly explored area of research (Lai *et al.*, 2017). Through this, a quantifiable definition of this has been described. Namely, that it is a 'discrepancy between perceived social abilities (observable behaviour), and actual underlying abilities' (Livingston, Shah & Happe, 2019, p.767; Lai *et al.*, 2017, Livingston & Colvert, 2019). Measurements of compensation have included self-report methods and observations (Dean, Harwood & Kasari, 2017; Hull *et al.*, 2019; Parish-Morris *et al.*, 2017), with evidence suggesting a positive correlation with IQ and executive function (Lai *et al.*, 2017; Livingston & Colvert, 2019). The complex experiences of compensation have been identified, though the realisation of these may only be achieved through collaborative qualitative methods (Livingston, Shah & Happe, 2019).

Camouflaging is considered by some as a recent concept, however, whilst the increase is not contested, initial considerations predate the recent surge (Wing, 1981a). The consideration was featured when considering the reasons for the disparity between male and female diagnoses (Wing, 1981a). Whilst dated, this study provided interesting applications to current study because of the discussion of female's ability to replicate norms and behaviours that elicit positive consequences (Wing, 1981a). Nevertheless, this study was not without criticism, namely that the samples included adults with a diagnosis of autism and there were limitations identified in the sample size and variety of demographic information (Fulton *et al.*, 2017).

The relevance of camouflaging stems from an awareness that it is typically enlisted in social situations (Dworzynski *et al.*, 2012; Tierney *et al.*, 2016). The concealing of difficulties can be labelled as camouflaging and can take the form of suppressing and hiding behaviours or repeating and replaying behaviours and interactions which are considered to have positive outcomes (Bargiela, Steward & Mandy, 2016; Kanfisz, Davies & Collins, 2017). The presence of socially desirable or 'normal' responses to situations and behaviours are found more in female samples, which may result in difficulties being internalised or misdirected, leading to a different diagnosis, or no diagnosis being made (Kirkovski *et al.*, 2013; Lai *et al.*, 2015; Ormond *et al.*, 2017). The link between camouflage and navigating social challenges is supported by Attwood (2007), who discusses pressures to 'fit in' through development induces coping mechanisms to be enlisted. Various behaviours have been cited as that which may be a result of camouflaging, for example, mimicking others' behaviour in social settings, and learning and replaying social scripts (Lai & Baron-Cohen, 2015). Whilst the driving force behind enlisting these behaviours is to reduce perceived negatives, retrospective accounts from autistic adults and clinical observations have identified that ensuring balance is important due to the detrimental costs of these behaviours (Lai *et al.*, 2017). Stress, exhaustion, overload, anxiety, and depression have all been reported through various studies over several years, however, this remains an area for additional consideration because of its complexity (Attwood, 2007; Boyd,

Woodbury-Smith & Szatmari, 2011; Lai *et al.*, 2011; Simone, 2010; Wiley, 1999; Williams, 1992).

Camouflaging has received a large range of consideration, with general definitions focusing upon enlisting compensatory mechanisms to hide difficulties and mimic perceived positive actions and behaviours (Dworzynski *et al.*, 2012; Tierney *et al.*, 2016). Irrespective of the specific definition, there is a level of agreement in them all, in that there is a difficulty to detect such behaviours, as well the process being learnt over time and is not actively innate (Attwood & Grandin, 2006). A recent paper by Halsall, Clarke and Crane (2021) utilises a multi-informant approach to explore camouflaging in autistic teenage girls. The focus was placed on the strategies used by these girls, with information collected from semi-structured interviews from girls, parents (mothers) and educators (Halsall, Clarke & Crane, 2021). This reinforces previous literature that identifies the impact of camouflaging, providing specific examples of impacting relationships, learning, and negative mental health. Furthermore, the experiences of inconsistent or unsuccessful attempts to camouflage were noted by parents and educators, with difficulties with friendships and experiences of rejection and isolation also being reported (Halsall, Clarke & Crane, 2021). Overall, this paper draws on a social constructionist perspective that shares similarities with the position adopted in this thesis, therefore, making it a central source of reference.

Female dominance in areas of social ability and communication has been considered, with conclusions focusing upon this being an enabling factor in masking and concealing deficits, as well as increasing the ability in other areas such as social impairment (Gould & Ashton-Smith, 2011). When reflecting on prior research into camouflaging, it should be acknowledged that the aims and presentation of research is influenced by philosophical approaches. Camouflaging research highlights the range of approaches, though two frequently cited are grounded theory approach and a positivist approach (Glaser & Strauss, 2009; Lai *et al.*, 2017). As described in the above section, research generates a range of data sets, from conceptual understandings of camouflaging to real life experiences. Specifically, a grounded approach will utilise research questions such as 'what is camouflaging in autism' to collect qualitative data to 'inform concept formation (Lai *et al.*, 2017: 962). In



comparison, positivist approach would *“operationalise camouflaging using existing, standardised measures and test for relevant hypotheses derived from the observations and findings...”* (Lai et al., 2017, p.962).

Whilst exploring philosophical and methodological approaches to research is not the purpose of this chapter, it is likely that these have influenced the sources used in this synthesis. Philosophical and methodological positions are expanded upon in chapter three.

#### **2.3.4.1 Camouflaging and Dyslexia**

The recognition of camouflaging has been more widely recognised in the field of Dyslexia (Alexander-Passe, 2015), through advanced coping strategies that aim to maintain the projection of normality or not to stand out (Alexander-Passe, 2010; Scott, 2004; McNulty, 2003). Learners with dyslexia have been described as conscious of their differences, finding solace in the portrayal of an alternative or secondary persona (Alexander-Passe, 2012; Scott, 2004). These strategies enlisted do not however come without risk, for example, when breaks occur in the externalised persona, it can be embarrassing, demonstrate vulnerability, and representative of being ‘other’, compared to their peer group (Alexander-Passe, 2015). Stigma and questioning about the validity of one's diagnosis has been cited (Snyder, Carmichael, Blackwell, Cleveland & Thornton, 2011; Green, Davis, Karshmer, Marsh & Straigh, 2005), in addition to perceptions of laziness and lower intelligence (Lisle, 2011). These incorrect and negative assumptions do not consider the efforts individuals go to so that they ‘fit in’ and achieve similar levels to their peer group (Denhart, 2008; Alexander-Passe, 2015). In addition, they may reinforce the need for these strategies to continue, irrespective of the exhaustion and illness that they may cause (Denhart, 2008; Rodis, Garrod & Boscardin, 2001).

## **2.4 Social domains**

### **2.4.1 Social aspects in diagnostic criteria**

Despite social communication and interaction difficulties being a predominant feature in autism diagnostic criteria (APA, 2013), only a small amount of research focuses upon interactions and social processes that occur in everyday contexts (Bottema-Beutel, 2017). Amongst research, the thought processes and psychological implications of autism are often separated from those studying bodily impacts (Robledo, Donnellan & Strandt-Conroy, 2012). These thought processes and psychological implications include social communication, behaviour, and interactional relationships with others (Leary & Donnellan, 2012).

The social competence of autistic individuals has been considered in research, with the most frequent explanation drawing upon the likelihood of their being a core deficit in social cognition (Chevallier *et al.*, 2012). However, females diagnosed as autistic are more likely to develop coping strategies and conceal their difficulties (Solomon *et al.*, 2012). Interestingly, Faherty (2006, p. 12) suggests that motivation to do this may also come from a desire to conform to 'assumptions that society places on the female gender'. Wilkinson (2008) goes on to further discuss females having a higher appreciation for social interaction as well as a higher motivation for positive outcomes and successful interactions.

Some of the difficulties that individuals may face when navigating the social world are somewhat comparative to the diagnostic criteria (APA, 2000; 2013). For example, face-to-face interactions include several possible difficulties for someone with an autism diagnosis, from difficulties in identifying and reacting to facial expressions and nonverbal cues, to the over stimulating and anxiety attributed to these types of interaction (Rump *et al.*, 2009; Smith *et al.*, 2010; Tager-Flusberg, Paul & Lord, 2003; Carter *et al.*, 2005; Dalton *et al.*, 2005; Joseph *et al.*, 2008).

Interpersonal relationships have specifically been considered, with conclusions focusing upon the importance of the groups an individual associated with in determining the behaviours and challenges faced (Tierney *et al.*, 2016). In addition, this has been extended to suggest that difficulties may be more apparent, and may lead to negative consequences, in typically female groups who have a high value placed upon discussion and interpersonal relationships (Goodwin, 2006).

#### **2.4.2 Social competency**

Social competency is linked with social skills, specifically, positive, and successful interactions being a marker of social competency (Rao, Beidel & Murray, 2008). Difficulties in the knowledge of some social skills, or inappropriate use of them is a characteristic of autism, with this indicating a lack of, or lower level of social competence (Stichter, Herzog, Visovsky, Schmidt, Randolph, Schultz, & Gage, 2010). For adolescents, this can include the initiation and maintenance of friendships, recognising and responding to bullying or conflict, and wider difficulties in navigating the social world (Stichter *et al.*, 2010). The extent that these difficulties present in everyone varies, for example, those with diagnoses of Asperger's and High Functioning Autism are considered likely to desire social interaction, with problems arising with the maintenance of them (Myles & Simpson, 2002).

Definitions of social interaction are viewed in the behaviour's individuals display, as well as their understandings and explanations of these (Wilkinson, 2008). With regards to social competency in female samples, these behaviours are understood and more highly present, in addition to an increased desire for successful interactions (Wilkinson, 2008). These differences provide support for the exploration of the navigation of social activities in a female sample. In addition to the consideration and awareness of positive social interactions, further research identifies that behaviours considered to be socially desirable are more frequently noted in female samples (Lai *et al.*, 2015).

The focus on social competencies draws upon findings considering the age of diagnosis or recognition of autism in males and females. Specifically, that for females, difficulties are considered heightened in the teenage years when social pressures, expectations and ideas surrounding compliance are at their highest (Moyse & Porter, 2015).

#### **2.4.2.1 Social capital**

Within the concept of the social world, understandings of social capital may provide theoretical explanations for the navigation strategies employed. The theory of social capital centres on the benefits that can be obtained through relationships with others (Portes, 1998). This term invariably has been interpreted in various ways, though that of Bourdieu (1986), whilst dated, may provide a transferable understanding to the topic of this paper. The broad cultural view reinforces that social capital is increased through certain groups, and therefore, may be an increasingly prevalent consideration among adolescents (Bourdieu, 1986).

When considering social support networks which children and young people engage with, taking a holistic view of both the formal and informal methods is beneficial in facilitating a children's rights and advocacy perspective (Coles, 2000; Pinkerton & Dolan, 2007). Specifically, in relation to the navigation of the complexities of the social world, Pinkerton, and Dolan (2007) postulate that an understanding of the networks of support adolescents have, will positively influence their transition to adulthood.

#### **2.4.3 Interventions and support networks**

Literature evaluating interventions for autistic individuals has mainly focused upon males alone, with the inclusion of females always being with males (Chan *et al.*, 2009). McVey *et al.*, (2017) examined the responses of males and females to the PEERS® Social Skills Intervention on Social Behaviour, with no significant differences by gender presenting. Additional social skills interventions are available for use in samples of autistic adolescents, however, evidence and evaluations of these view them as unable to identify potential gender differences (Palmen, Didden & Lang, 2012; White, Keonig,

& Scahill, 2007). The perceived superiority of PEERS® draws upon multiple sites' validity measures, as well as its direct consideration of relational aggression (Laugeson, Frankel, Gantman, Dillon & Mogil, 2012; Schohl *et al.*, 2014; Yoo *et al.*, 2014). However, limitations in studies of this programme are cited, specifically, the lack of qualitative measures that include participants' experiences. Further studies into the use of social skill interventions may benefit in evaluating which components are most beneficial for autistic females, as well as the effect of the gender balance in groups in which interventions are developed. An example of this would address biological changes during the period of adolescence and the subsequent self-care needs of females (Jamison & Schuttler, 2017).

Social skills training and support materials have been available for some individuals, though the aim to provide these in real-life and meaningful settings has been suggested to have room for improvement, specifically in ensuring they target the female phenotype of autism (Gould & Ashton-Smith, 2011). Social skills training groups have been the target of much research and debate, for example, the autistic community has been divided over the behavioural intervention, Applied Behaviour Analysis (ABA) (Pantazak, 2019). There are two main positions adopted in this debate. The first, primarily from neurodiversity activists, views this treatment as breaching consent and human rights as it is perceived as a tool to cure autism (Pantazak, 2019). The other, often advocated by health clinicians highlights the evidence-base behind ABA along with the ability to deliver 'results', positioning autism as a source of challenge (Odom, Collet-Klingenberg & Rogers, 2010).

Pantazak (2019: 3) describes the purpose of this intervention as 'teaching one to leave given behaviours behind and to adopt new ones' and utilises behavioural approaches to reinforce 'positive' and discourage 'negative' behaviours. Opposers of this treatment commonly position themselves against the medical model of disability, as such, reject the need for treatment or a cure to be found (Kirkham, 2017).

Autistic people's support networks and environments can have a positive influence on their experiences of adolescence and how they can develop their identity and place in the world (Bottema-Beutel *et al.*, 2020; Crocetti, 2017). Studies such as Sagers (2015) utilise autistic students' contributions and identify the role of teachers as providing support that is critical. Successful relationships have been conceptualised as built on mutual trust through a developed relationship over time (Cai & Richdale, 2016; Sagers *et al.*, 2015). However, it should be acknowledged that the support desired by an individual can vary (Bottema-Beutel *et al.*, 2020). For example, subtle forms of support were described favourable when seeking to reduce possible stigma arising from receiving support (Bottema-Beutel *et al.*, 2016). Additionally, parents are viewed as a support network, ranging from organisation or practical assistance to emotional support to help navigate the increasing complexities of the social world (Bottema-Beutel *et al.*, 2020).

#### **2.4.4 Friendships**

The developmental importance of friendships is not a new belief, neither are the purpose and benefits on one's skills and abilities (Sedgewick, Hill & Pellicano, 2019). Specifically, they have been cited as aiding the development of social skills and providing social and emotional support (Cutting & Dunn, 2006; Dunn, 1988; Dunn & Cutting, 1999; Demir & Urberg, 2004; Dumont & Provost, 1999). As difficulties in social domains are recognised in diagnostic criteria (APA, 2013), there exists to be an assumption that this means individuals do not desire friends and that they do not have social motivation (Chevallier *et al.*, 2012). However, this has been challenged by various scholars (Bauminger *et al.*, 2008; Calder *et al.*, 2013; Sedgewick *et al.*, 2016, Kasari *et al.*, 2011), who describe many autistic young people as having friends, being involved with social and educational networks, and have a desire for interaction with peers. A review of research considering pre-adolescent individuals (aged between 10 and 14) document findings of individuals having a smaller number of friends (compared to neurotypical children), though, they were highly satisfied with them (Petrina *et al.*, 2014). Whilst interesting findings emerged, the focus on children in this review leaves the experiences of adolescents neglected, as well as experiences of females (Sedgewick, Hill & Pellicano, 2019). Where female samples were considered,

they were often limited to individuals not educated in mainstream settings, thus again leaving a gap in our knowledge (Sedgewick *et al.*, 2016). The need for exploration of female experiences is supported by the long-established gender differences in friendships within neuro-typical samples and the gender differences in how children are socialised from birth (Aukett *et al.*, 1988; Caldwell & Peplau, 1982; Smith & Lloyd, 1979). In sum, findings from Sedgewick, Hill and Pellicano (2019) demonstrate how females require adapted strategies and support in understanding and successfully navigating the social world and expectations placed on them.

Within the specific topic of friendships, scholars have been defining and exploring friendship, alongside the effect of gender for over thirty years (Foggo & Webster, 2017). Specifically, research findings indicate that females can spend up to nine hours conversing with friends over a week, whereas males are more likely to spend this time interacting through structured games and sporting activities (Lever, 1978; Raffaelli & Duckett, 1989). Despite the apparent limitations in the application of these findings due to the date it was conducted and the focus on neuro-typical samples, more recent study has mirrored these gender differences in samples of autistic adolescents (Kuo, Orsmond, Cohn & Coster, 2013). Sedgewick *et al* (2015) extend this and suggest that gender not only links to the activities chosen, but also the understandings and expectations of friendships.

With these considerations of friendship, it may be that the perceived difficulties and deficits in areas of social interaction are because of social exhaustion and anxiety, not because skill or knowledge is lacking (Ciampi, 2012; Simone, 2010). Difficulties may continue to go undetected as girls tend to be ignored and overlooked, rather than being actively rejected in social activities and interactions (Dean *et al.*, 2014).

In diagnostic practice, concepts of friends and friendships require an increased consideration due to their complexity (Bargiela *et al.*, 2016). Such challenges within friendships are increasingly prevalent in female adolescents, because of which, appropriate support and understanding is of great importance (Hartley & Sikora, 2009).

### 2.4.5 Hidden curriculum

The formal academic curriculum children and young people are exposed to has been suggested to require additional teachings of the less formal curriculum, or hidden curriculum (Myles & Simpson, 2001; Oliver & Lalik, 2004; Vang, 2006). Initially identified and cited by Jackson (1968), the hidden curriculum has been described as that of unspoken rules, social values, norms, and attitudes which affect the perceptions and views of behaviours in a variety of settings (Jackson, 1968). Furthermore, the importance of individuals being able to identify and comply with these social rules and expectations in a wide range of settings is a result of the negative impacts if one fails to meet these (Lee, 2011). This can present challenges, for example, for autistic individuals, as these rules and expectations are rarely explicitly taught (Myles, 2005). In school settings, the hidden curriculum has been split into several areas of assumed knowledge:

*‘(a) teacher expectations, (b) teacher-pleasing behaviors, (c) students who potentially make good friends compared to those whose actions are less than honest, (d) behaviors that attract positive attention from teachers and peers, and (e) behaviors that are considered negative or inappropriate by teachers and peers’* (Lee, 2011, p.142; Myles & Simpson, 2001).

The difficulties associated with the hidden curriculum are enhanced by the cultural and societal specificity of expectations, unspoken rules and importance placed upon social interaction and communication (McAfee, 2002). Additionally, age can influence the hidden curriculum through expectations of behaviour steering away from social appropriateness to the ‘cool’ and ‘not cool’, specifically during adolescence (Lee, 2011, p.142; Myles, 2005).

The navigation of the social world shares close links to the hidden curriculum, which Myles and Simpson (2001, p.279) describe as being the things ‘that we are not taught directly yet are assumed to know’. This concept includes several rules, norms and expectations that evolve and develop; however, they all remain implicit and unstated



(Myles, Trautman & Schelvan, 2013). Many autistic individuals experience difficulties in understanding such implicit concepts, and the consequence can be daily anxiety (Dubin, 2009). This anxiety has been explained as influenced by the social interaction demands in educational establishments, but also an awareness that implicit norms have been misunderstood or missed entirely (Portway & Johnson, 2005; Lee, 2011; Moyse & Porter, 2015).

The overlooking of difficulties experienced in autistic females can have consequences, specifically, without appropriate support, individuals are at an increased risk of academic underachievement and mental health issues during adolescence (Kuusikko *et al.*, 2008; Ashburner *et al.*, 2010).

#### **2.4.6 Romantic relationships**

Romantic relationships and sexuality are more recent considerations in adolescent populations (Bertilsson Rosqvist, 2014). This contrasts with the previously held belief that many autistic individuals are either asexual or find sexuality and relationships extremely problematic (Dewinter *et al.*, 2013; Kellaher, 2015). However, some research identifies that the difficulties faced differ from those experienced by typically developing (TD) individuals (Dewinter, Graaf & Begeer, 2017). Studies of autistic adults without cognitive impairments have found between 17% (Balfe & Tantam, 2010) and 73% (Strunz *et al.*, 2017) of participants were in a romantic relationship or living with a partner. Of those that were single, a third did not identify this as a negative (Strunz *et al.*, 2017). Individuals that reported being single identified a variety of reasons they felt unable to be in a relationship, for example, the exhaustion associated with contact with a partner (Dewinter, Graaf & Begeer, 2017).

Though these findings give us some guide about the experiences, the results vary considerably and is not yet clear how romantic relationships are navigated and managed by autistic adolescents (Dewinter, Graaf & Begeer, 2017). Part of the limitation of the research outlined above is due to their small samples, for example, one of the larger participant numbers was 141 (Byers *et al.*, 2012). In addition, self-

report methods are only more recently being employed (Dewinter, Graaf & Begeer, 2017).

## **2.5 Technological developments**

### **2.5.1 Technology and social media**

Within the study of the social world, technological advances and the growing prevalence of social media may influence the direction of research in the field of autism, specifically because of the transformation of how people communicate (Abel, Machin & Brownlow, 2019). In addition, web-based technological developments expand the remit of social inclusion, as well as changing expectations and experiences of communities and networks (Clegg, 2010). The use of the internet for social and communicative purposes has been suggested to be ground in the theory of uses and gratification (Whiting & Williams, 2013). Examples of such uses include meeting others, maintaining, and monitoring relationships, as well as seeking information (Ellison, Steinfield & Lampe, 2006; Machin, Jeffries & Machin, 2014). The use of social media amongst autistic individuals may align with the preferred, or less stressful process of non-face-to-face communication (Bagatell, 2010; Burke, Kraut & Williams, 2010).

### **2.5.2 Internet usage**

The rapid growth of internet usage among children and young people has produced various statistics which seek to measure the breadth of its growth (Ólafsson, Livingstone, & Haddon, 2013). For example, in a cross-cultural study of internet usage in young people aged between nine and sixteen, Livingstone *et al.*, (2011) found that over 60% went online every day. The effects of the growing use of the internet have been measured, though mainly for benefits in psychological and emotional well-being (Tynes, 2007). However, the negative effects and potential for it allowing children or young people to be at risk are a concern for some researchers (Bannon *et al.*, 2015).

The usage of the internet in the day to day lives with children and young people with additional learning needs has been stated as being like rates found in the wider population (Del-Manso *et al.*, 2011; Didden *et al.*, 2009). Specifically, in relation to this study, Kowalski and Fedina (2011) identify the specific diagnosis of Asperger's syndrome in the studied populations. The use of such technology has been cited as having many purposes, including to aid learning, to access entertainment and to socialise with others (Didden *et al.*, 2009). This may provide a medium to increase positive social interactions with peers, which is supported by the selection of individuals identified in having difficulties in forming friendships in more traditional settings (Bellini, 2004; Carr, 2006; Bannon *et al.*, 2015).

## **2.6 Perceptions among society**

### **2.6.1 News media**

The public interest in disabilities, including autism, has resulted in the media presenting dramatisations of disabled people and the impact on their lives (Bailey, 2011; Richardson, 2010). These have been positioned as increasing the awareness and familiarity of autism as a diagnosis, though does not influence the stigma autistic people face (Broderick, 2010; Holton, 2013). Alternatively, in newspapers, perceptions and depictions of autistic people have focused upon postulated causes and cures, for example, unsupported links with vaccinations (Clarke, 2010). The consequences of these presentations of autistic people include inciting stigma to be attached to the diagnosis (Darke, 2010; Falk, 2001). Phase two (chapter five) discusses the role of the news and framing in more detail.

### **2.6.2 Stigma and misconceptions**

Stigma or stigmatisation focusing on physical or mental traits that are positioned negatively, as not meeting social norms and expectations, thus rendering a divide rather than inclusion (Stuart *et al.*, 2012). The link with discourse is highlighted by Hinshaw (2007) who highlights the shame individuals experience through the labels and narratives portrayed. Modifications to diagnostic criteria, positioned as a catalyst for increasing diagnoses, prompted an increase in autistic narratives in public media

(Holton, Farrell & Fudge, 2014). Goffman (1963) provides foundations to the concept of stigma, focusing on the difference between authentic experiences and societies expectations. Corrigan, Roe and Tsang (2011) add to this, describing stigma as encompassing prejudice, stereotypes and discrimination that result from biased societal understanding and misconceptions about an individual or group (Corrigan, 2000). Within stigma, four types have been identified and defined (Mitter, Ali & Scior, 2019), with two being particularly relevant for autistic people. The first, public stigma, focuses on the beliefs held in society about a specific group of people (Bos *et al.*, 2013). The second, self-stigma, is described as when an individual is aware of misconceptions and stereotypes about them or a group they identify with, and internalise the public stigma (Ali *et al.*, 2012; Mitter, Ali & Scior, 2019).

## **2.7 Wider concepts**

### **2.7.1 Concept of inclusion and additional needs**

The diagnosis of autism fits into a wider area of discipline of inclusion and additional needs (Hodkinson, 2009). Definitions of this are wide and are varied, though a large number focus upon the education and positive inclusion. For example, Robinson (2017:164) describes inclusion as

*“the process through which education systems respond to diverse learners in ways that enable participation, equal opportunities, respect for difference and social justice”.*

Whilst this definition focuses upon an educational system, it documents the importance of practices which enable participation. Thus, it supports the need for research to likewise consider the inclusivity of the method and settings within data collection.

In addition to definitions outlined above, social inclusion remains an ongoing challenge as the concept lacks clarity and a shared definition (Amado *et al.*, 2013; Bigby, 2012a, 2012b; Cobigo *et al.*, 2012; Duggan & Linehan, 2013; Hall, 2009; Overmars-Marx,

Thome'se, Verdonschot, & Meininger, 2014). When attempting to measure social inclusion, having a clear definition can assist in standardising the methods and methodologies chosen, in turn, increasing the applicability of findings (Amado *et al.*, 2013). Despite this challenge, social inclusion (or lack of) is identified as one of the key factors influencing the well-being of individuals with disabilities, including autism (Buntinx & Schalock, 2010). Furthermore, it is a key component in legislation, namely in the United Nations Convention on the Rights of Persons with Disabilities (Quinn & Doyle, 2012). Discussions around developmental disabilities describe social isolation as being a common experience (Bigby, 2008; Forrester-Jones *et al.*, 2006; Milner & Kelly, 2009), with additional findings suggesting these individuals' social networks are predominantly with family members and professionals (Lippold & Burns, 2009; Simpican *et al.*, 2015). Walker *et al.*'s (2011) description of social inclusion focuses upon how society accepts and responds to people with disabilities in settings such as schools, work, and community environments. As such, this reinforces how the subjectivity of communities' attitudes towards people with disabilities can influence the experiences and extent of social inclusion (Simpican *et al.*, 2015). Participation or presence within a social environment does not denote social inclusion, as there is the need for a feeling of belonging or fitting in for this to be achieved (Power, 2013). This challenges the extent that quantifiable measures and objectivity can truly measure real life experiences (Hall, 2010; Cobigo *et al.*, 2012).

Interpersonal relationships and social participation are credited as benefiting quality of life (Schalock *et al.*, 2005), as well as being necessary for successful social inclusion (Asselt-Goverts, Embregts & Hendriks, 2013; McConkey & Collins, 2010a). Thus, when considering autism, this may be an area warranting consideration, for example, whether social inclusion is achieved, or inherently desired (Simpican *et al.*, 2015). This gives another example of an area within the social world where challenges, or alternative ways of navigation, may be identified in adolescent autistic females (Simpican *et al.*, 2015).

### 2.7.2 Autistic voices in research

Happe and Frith's (2020) annual research review provided a summary of the key points made, one of which, serves as a poignant reminder of the importance of the methodological approach in autism research. Further, it presents a clear instruction of what should be done when conducting empirical study to ensure that findings are both useful and a true representation of the sample's experiences.

*“A participatory research approach that includes the views of the autism community is needed to ensure that research priorities are constantly monitored and reviewed” (Happe & Frith, 2020, p. 229).*

When reflecting on well-being, autistic people have typically been excluded from contributing to research (Lam *et al.*, 2020; Pellicano & Stears, 2011). As a result, their experiences and opinions do not contribute to knowledge production (Bölte & Richman, 2019; Fletcher-Watson *et al.*, 2019). Considering quality of life, reports included in research often come from caregivers and professionals (Billstedt *et al.*, 2011; Gerber *et al.*, 2011), though these reports have been criticised as not mirroring autistic people's views and experiences (Sheldrick *et al.*, 2012; Shipman *et al.*, 2011).

#### 2.7.2.1 Participatory research

In the specific field of autism, participatory research has been described as enabling meaningful input, as well as improving benefits and outcomes relevant to the population (Long *et al.*, 2017; Fletcher-Watson *et al.*, 2019). Whilst dated, a frequent tool enlisted to determining the different types of research participation is Arnstein's ladder of participation (Arnstein, 1969). This ladder visually represents the levels of participation, from that of no power, to devolved power (Arnstein, 1969). Within autism research, the conceptualisation of participation is on the most part that of no power or tokenistic forms of power (Nicholaidis *et al.*, 2011). A review of the perceptions of participatory research among the public, practitioners, and researchers, found contrasting views on the levels of this research (Pellicano *et al.*, 2013). Namely, researchers rated higher levels of engagement than that suggested by autistic individuals and their families (Pellicano *et al.*, 2014). In addition, funding and output in the United Kingdom was not considered to align with practitioners, individuals, and

families' view of what should be prioritised within research (Fletcher-Watson *et al.*, 2019; Pellicano *et al.*, 2014). Various explanations for this have been considered, with Nicolaidis and Raymaker (2015) suggesting the traditional field of scientific enquiry is not best placed to conduct research in this field.

A key strategy to improve the social applications of autism research is through participation (Riccio *et al.*, 2021; Fletcher-Watson *et al.*, 2018; Raymaker & Nocolaidis, 2013). Specifically, including autistic people through the conceptualisation of research, conducting the research, and disseminating the findings aligns closely with participatory autism research (Nicoladis *et al.*, 2019; Raymaker, 2013).

### **2.7.2.2 Autistic people positioned as vulnerable**

Various definitions of vulnerability exist, with variation between different fields, such as within educational, social, and research settings. For example, in the field of health and social care, the Department of Children, Schools and Families described it as being 'children under the radar' (House of Commons, 2008). In comparison, Moore and Miller (1999, p. 1034) define vulnerable individuals as people who 'lack the ability to make personal life choices, to make personal decisions, to maintain independence and to self-determine'. Broadly in the field of research, difficulties can present when including individuals perceived as vulnerable, however, in relation to children and young people, the lack of inclusion from them through first-hand accounts is considered by some to increase vulnerability and marginalisation among society (Brown, 1998; Hill *et al.*, 2004, Aldridge, 2012). Such beliefs centre on rights-based approaches and are supported by the international mandate of the United Nation Convention on the Rights of the Child (UNCRC, 1989). On the other hand, excluding participants because of their vulnerability may inadvertently reinforce the stigma associated with their protected characteristic (DuBois *et al.*, 2012; Levine *et al.*, 2004; Schrems, 2014). To balance this, both policy and research has outlined how the challenges if including these populations can be overcome and managed, namely through appropriate consent, and information being provided in a way and medium that is appropriate (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities

Research Council of Canada, 2014; CIOMS, 2002; World Medical Association, 2013; Zion, Gillam & Loff, 2000) The definition of vulnerability being a relational feature, derived from power asymmetries, is growing in discussions in literature, for example, that between participants, researchers, and the institutions they represent (Bell *et al.*, 2014; Bracken-Roche, Bell & Racine, 2016; Schrems, 2014). The awareness of this may lead to research better serve participants, increasingly so if measures empowered, and promoted the agency and autonomy of participants within the research context (Bracken-Roache, Bell & Racine, 2016). Overall, there have been suggestions that the widespread definition and thus application of understandings of the term are 'vague' (Bracken-Roche *et al.*, 2013, p.2; Schroeder & Gefenas, 2009).

Bracken-Roach *et al.*'s (2013) comprehensive review of literature and the ethical concept of vulnerability resulted in several groups in society having the potential to be considered vulnerable within research. This considered, there were conditions to when a group may, or not, be considered vulnerable. Children, minors, and young people were cited as vulnerable as they had limited capacity and freedom to consent (Rogers & Ballantyne, 2008, Wrigley, 2015), or would be more likely to experience harm due to their stage of development (Wrigley, 2015). Interestingly, the reason for this group being considered vulnerable was not clearly explained or had no explanation in three of the reviewed documents (Bracken-Roache, Bell & Racine, 2016; Macklin, 2003; Schrems, 2014). This may be suggestive that societies' overall view of children and young people being vulnerable has cemented within knowledge, thus is now just considered facts. The effects of inclusion of this group were discussed through their vulnerability to coercion and agreement with someone perceived to be in a higher position than themselves (Deslauriers *et al.*, 2010).

Another example of a group considered vulnerable which is relevant to this thesis are individuals with mental illness or mental health difficulties (Bracken-Roach *et al.*, 2013). This vulnerability has been explained through previous mistreatment during research (Wrigley, 2015), as well as the perceived increase in possible discomfort, stress, and adverse responses (Bracken-Roache, Bell & Racine, 2016). When considering the inclusion of 'vulnerable' participants, we should be mindful of the



rights-based perspectives which outlines how disability does not automatically define an individual as being vulnerable, rather, the lack of access, information, and support, are the factors that intensify vulnerability (Lang *et al.*, 2011). Furthermore, this approach champions every individual having an equal opportunity to access services, though the nature of how this is done, and the support needed, should vary dependent on the individuals' needs (Mannan *et al.*, 2012).

### **2.7.3 Legislative context**

Landmarks in the field of autism have been identified, for example revisions of the DSM (APA, 2000; 2013). In addition, landmarks in education, inclusion and children's rights equally have developments of note. Specifically, The Equality Act (2010) and the UNCRC (1989) have been significant in research and practice. These legislative frameworks provide a structure that must be followed when conducting research, presenting the legal rights and expectations to be followed.

#### **2.7.3.1 United Nations**

The UNCRC is within the United Nations (UN) system of human rights (Beazley *et al.*, 2009). The main emphasis focuses upon the rights and freedoms of all, irrespective of age, such as respect, dignity, equality, expression, and non-discrimination (Beazley *et al.*, 2009). This consideration of civil and political rights for children has received a large amount of attention in academic debates and discussions (Invernizzi & Williams, 2007).

The UNCRC is considered to have strengthened the consideration and awareness of including children and young people's view in matters directly affecting them, in methods that are authentic and meaningful (Lundy, 2007). Specifically, Article 12 of the UNCRC emphasised children's right to express their views and draws upon concepts of children being valued as social actors in their own right (Burchardt, 2005; Cavet & Sloper, 2004; Lewis *et al.*, 2007; Emmel *et al.*, 2007). The exclusion of vulnerable samples, for example those with additional needs, has been recognised as

an area of significant problem, as well as suggesting that this places such individuals a double denial of their rights (Lundy, 2007: p935).

In relation to children in research, the UNCRC gave state parties the responsibility of reporting the progress of achieving human rights of children, including those in areas where reliable information and appropriate research methods had yet to be developed (Beazley *et al.*, 2009).

The right to be properly research is represented through four key articles, in which clear applications for rights-based research are identified (Ennew & Pateau, 2004, p. 29). These considerations are supported through the changes in children and young people becoming participants within research, as opposed to being subjects to be studied (Aldridge, 2012).

Relevant article of the UN Convention on the Rights of the Child	What it means for rights-based research
Article 12.1	<ul style="list-style-type: none"> <li>Children's perspectives and opinions must be integral to research.</li> </ul>
Article 13.1	<ul style="list-style-type: none"> <li>Methods need to be found, and used, to help children to express their perspectives and opinions freely in research.</li> </ul>
Article 36	<ul style="list-style-type: none"> <li>Children must not be harmed or exploited through taking part in research.</li> </ul>
Article 3.3	<ul style="list-style-type: none"> <li>Research must conform to the highest possible scientific standards.</li> <li>Researchers must be carefully recruited and supervised.</li> </ul>

*Table 3: A table taken from Ennew and Plateau (2004, p. 29) describing the relevant articles from the UNCRC in relation to research.*

In addition to the UNCRC, another relevant publication was adopted and brought into force in 2008 (Mannan *et al.*, 2012). This, The Convention on the Rights of Persons with Disabilities (UN CRPD) is the first international document that focuses on protecting the rights of individuals with disabilities (United Nations, 2006; United Nations Enable, 2008-2011). Furthermore, it is legally binding, and as such, sets out the legal obligations on states to protect, promote and identify the rights of all individuals with disabilities (United Nations Enable, 2008-2011). The motivation for this policy to be developed and adopted, as well as its scope of application, focus on the levels of the world's population that have disabilities (Mannan *et al.*, 2012; WHO & World Bank, 2011). An estimate of fifteen percent of the population worldwide has a disability or are considered disabled, which equates to over one billion people who may not be able to access, engage with, and benefit from opportunities of the mainstream population (WHO & World Bank, 2011).

Review and analysis of this convention identify its grounding in a social model of disability (Stein & Lord, 2009; see 2.6.2.2 for discussion). In addition to its legal and political guidance for development, it also spans a variety of fields, addressing a range of human rights, for example, civil, economic, social, and cultural rights (European Foundation Centre, 2010). Lang (2009) extends this to surmise that it raised the profile of disability to a level that had not been achieved previously, with Stein *et al.*, (2009) citing the widescale participation of persons with disabilities during its development to explain the extensive support worldwide.

Core concepts of Human Rights have been identified and discussed as to how these are influenced and supported by the UN CRPD (2006). Specifically of note are participation, protection from harm, autonomy, and contribution (Mannan *et al.*, 2012). Whilst these primarily were discussed in relation to evaluating policy and guidance documents, they provide a clear and concise summary which can enhance

understanding within this specific thesis. These also demonstrate the links with concepts of the UNCRC and the Equality Act (2010), presenting a description of each core concept.

### **2.7.3.2 The Equality Act**

The Equality Act (2010) focuses upon the requirement of educational establishments to ensure individuals are not at a disadvantage compared to their peers by factors as a result of disability. In addition, it demonstrates the progression in aiming to remove barriers to learning and participation (Fina & Cera, 2015). Whilst not specifically focused upon including these individuals in research, the movement towards positive inclusion support the need for research to be conducted to ensure that barriers do not exist, and any difficulties are managed. Furthermore, this act provides a legally binding agreement to provide inclusive education (Fina & Cera, 2015).

In addition, whilst the UN CRPD does not explicitly state a definition of disability, it does however cite the individuals which are protected by it as being ‘those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’ (United Nations, 2006, Article 1). As such, it shares close aims and principles to those within The Equality Act (2010).

### **2.7.4 Models of disability**

Models of disability ‘define disability, determine casual and responsibility attributions, influence professional practice, drive payment systems, and guide legislation’ (Smart, 2009, p.3). For example, they are viewed as the underlying structure for large diagnostic systems, including the Diagnostic and Statistical Manual (APA, 2013). These models frame the views surrounding where disability ‘comes from’, implications for society and actions that should be implanted to respond to it (Dirth & Branscombe, 2017). There are two main models that are described in the literature: the deficit or medical model and the social model.

#### **2.7.4.1 Deficit or medical model**

The concept of social relationships and interactions is often referenced in relation to autism, though this is frequently portrayed as a difficulty and area where deficits are prevalent (Feinstein, 2010; Verhoeff, 2013). In addition, reports from parents and clinicians frequently reference behaviours considered 'odd' or 'unusual' which require support (Waltz, 2014). Davidson and Henderson (2010, p.156) describe the representation of autistic individuals being 'socially incapable and isolated'. Views of such 'impairments' support the need for a specific consideration of how autistic individuals navigate the social world, with some understandings going further, explaining it as an 'enclosed space' (Hewetson, 2002; Sarrett, 2011), or part of being part of a different 'neurological class' (Duffy & Dörner, 2011, p.211). This view has been investigated within young people, specifically, that putting time and effort into 'fixing' difficulties is linked with a goal and focus upon fitting in (Brownlow, 2010, p.17).

Such model of deficit continues to be adopted in various professions, with it forming an integral part of autism assessments (Connor *et al.*, 2008). During such assessments, areas of difficulty, impairment, or deviation to the considered norm, reinforce the deficit model as well as contributing to the 'cause and cure' model of disability, with a goal of preventing and reducing autism incidence and symptomology (McGeer, 2004; Dawson, 2008). The measurement of ability, or disability, during childhood and adolescents, supports the sociological view of childhood as being a time for development and a separate entity to adulthood (Blakemore & Choudhury, 2006).

Similarly, to the deficit model, the medical model of disability has been identified as providing challenges. The scale of this model being enlisted is demonstrated through it being the dominant model enlisted when conducting autism research (Graby, 2016, cited in Woods, 2017). In addition, the autism discourse is dominated by the focus upon it being a disorder and a deficit (Woods, 2017).

#### **2.7.4.2 Social model of disability**

Our understandings of disability fall on a spectrum, with social and medical models being at either end (Manago, Davis & Goar, 2017). In contrast to the deficit focused medical model, the social model views impairments as being behaviours made disabling through a lack of societal accommodation (Oliver, 2013; Oliver & Barnes, 2012). A lack of societal accommodation includes a range of needs which may present, for example in psychological, cognitive, physical, and intellectual domains (Landsman, 2009; Smith, 2004). Positive identities are adopted by the social model, transferring to promote inclusion and accessibility in political and legal frameworks (Oliver, 2013; Shakespeare, 2004). This model asserts that the extent in which a diagnosis disables an individual can be influenced by societies response to the needs and requirements an individual has (Baker, 2011).

#### **2.7.4.3 Alternative perspectives on defining and categorising autism**

More recently, these representations have been challenged, with descriptions focusing upon autism not being an absolute barrier, but an influence which shapes social interactions and experiences (Hacking, 2009). As a result of this development in understanding, research and promoters for inclusivity have championed using autistic people to shape and lead research (Milton & Bracher, 2013; Milton, 2014), as well as extending the neurodiversity studies and considered in studies of social experiences (Bergenmar *et al.*, 2015; Runswick-Cole, 2014). These changes are rooted in understandings of all individuals being social actors (Coleman-Fountain, 2017).

Various proposals have been made as to how autism should be defined, with each being evaluated and criticised for their limitations. However, Jaarsna and Welin (2012) provide us with an understanding which is inherently positive and demonstrates the individuality of childhood, experiences, and perceived difficulties (Miyake & Friedman, 2012). This definition focuses upon the neurological basis of autism and describes how considered typical developmental and skill trajectories are extended to include

the presentation of autism, again reinforcing that ‘no two people are alike’ (Tincani *et al.*, 2011, p.81).

A study by Coleman-Fountain (2017) encompassing these principles of inclusivity, did however document some possible limits in their findings. Namely, as the researcher was not autistic, there was a lack of a shared understanding or ability to compare various experiences and viewpoints (Bertilsson Rosqvist *et al.*, 2013; Brownlow *et al.*, 2015). The negative view is reinforced by societal attitudes and focus upon self-improvement and development, specifically, some teachings for children and young people focus upon the need to avoid disruption of social norms and expectations (Bertilsson Rosqvist, 2012).

### **2.7.5 Well-being and mental health**

Literature on student well-being is overall plentiful, though, there is a lack of research that specifically focuses upon autistic students (Danker, Strnadova & Cumming, 2019). Subjective well-being (SWB) is highly valued as it is linked to more successful work, health, and social relationships (Lyubomirsky, Sheldon & Schkade, 2005). SWB within autistic individuals has featured in only a small amount of research, which yield inconsistent and variable findings, of which, gender has been at the root of disparities (Begeer *et al.*, 2017). More often, research focusing on autistic individuals considers Quality of life (QoL) (Begeer *et al.*, 2017). QoL encompasses several elements, including emotional well-being, social and material well-being, development, and activity (Felce & Perry, 1995). Suggestions that individuals, specifically children, that have an autism diagnosis, have lower QoL than neuro-typical children, are considered to lack direct evidence documenting the SWB in both groups (Van Heijst & Geurts, 2015). This limitation is because of small sample sizes in research, an imbalance of the proportion of males and females included in the studies, as well as a predominant focus upon measures of functioning as opposed to well-being (Kamp-Becker & Schröder, 2011; Shipman *et al.*, 2011; Tavernor & Barron, 2013; Waters *et al.*, 2009).

Research into the incidence of mental health difficulties in adolescents suggests that over the last thirty years, there has been a substantial increase (Collinshaw,

Goodman, & Pickles, 2004). In addition, individuals with additional needs can also be at an increased risk of experiencing mental health difficulties (Rose *et al.*, 2009; Office for National Statistics, 2008). Whilst dated, research conducted by Ghaziuddin, Wiederman-Mikhail and Ghaziuddin (1998) support suggestions that autistic individuals are the most vulnerable within the category of additional needs (Green *et al.*, 2005). However, limitations of this research have been documented, specifically that of their equivocal nature and methodological flaws (Hebron & Humphrey, 2014).

Compensatory mechanisms enlisted to disguise difficulties, for example camouflaging, are considered to result in low mental health in samples of autistic individuals. Links between compensation and negative effects on mental health have specifically considered depression, anxiety, and suicidal ideations (Cage & Troxell-Whitman, 2019; Cassidy, Bradley, Shaw & Baron-Cohen, 2018; Livingston & Colvert, 2019). Whilst the reason and cause lacks agreement, the experiences of unsuccessful compensation have been postulated as being instrumental in reducing self-esteem and well-being (Livingston, Shah & Happe; *in press*). In addition, the executive function and other cognitive skills enlisted to compensate are finite and a depletable resources (Powell & Carey, 2017). Caution should be given to these explanations as research has generally presented a theoretical or correlational framework, which has a limited ability to identify the strategies underlying compensation (Livingston, Shah & Happe, 2019).

Interesting considerations of anxiety have identified in samples of autistic individuals, specifically in that levels of anxiety are considered to increase during adolescence, an opposite pattern than that identified in typically developing individuals (Kuusikko *et al.*, 2008). The differences during the period of adolescence can be seen to support the need for the focus upon this stage of development, as well as providing background considerations for the study prior to its commencement.

Research into various mental health difficulties, such as depression, anxiety, and externalising behaviour difficulties, has however elicited wide estimates of prevalence



(White *et al.*, 2009; Widmer-Mikhail & Ghaziuddin, 1998; Kim *et al.*, 2000; Beverton, Tone & Enfield, 2006). Challenges in the identification of mental health difficulties have been cited, specifically the ability to differentiate from behaviours and experiences to be expected as a result of an autism diagnosis (Rose *et al.*, 2009). Some research has shown caution to estimates of mental health difficulties due to their consideration of limited unprompted reporting by individuals (Russel & Sofronoff, 2005). In comparison, when enlisting regular dialogue and collaborative strategy, self-initiated dialogue and discussion of difficulties have been recorded (Hebron & Humphrey, 2014).

### **2.7.6 Disciplinary position of thesis**

To provide a background to this thesis, it is important to acknowledge where it is positioned among other work. Through the synthesis above, several disciplines have been touched on, including education, health, social care, and disability studies. As a result, it does not fully ascribe to one discipline, but draws on elements from each, often described as cross-disciplinary. An in-depth analysis of these is beyond the scope of this synthesis, with it being viewed as more appropriate to categorise the work within the philosophical and methodological worldview of the researcher. This is explored in chapter three.

### **2.8 Summary of chapter**

This chapter has provided a summary of previous research in the field, as well as identifying areas where it could be developed further. Also, various considerations for future research have been identified, as well as themes surrounding the basis of this upon a social constructionist view of research (Cresswell & Poth, 2017). This included highlighting and defining conceptual frameworks to consider throughout the thesis.

Through the review of literature, possible themes of areas encompassed by the term social world have been identified, as well as a consideration of these in wider populations. Reviewing previous literature has enabled awareness to be raised as to

the principles of research, the views of participants, and considerations of vulnerable participants.

## **Chapter 3: Methodology, Methods and Study Design**

### **3.1 Introduction to the chapter**

This chapter aims to outline the researchers positioning (Harre *et al.*, 2009) , as well as how this informs the methods and methodology used to explore the given topic. Specifically, the ontological and epistemological positions aim to explain the theoretical underpinnings of the study aims and its design (Wilson & McCormack, 2006). This chapter will also briefly consider alternative approaches that could have utilised. Overall, this study utilises two approaches, the first, Foucauldian Discourse Analysis (Willig, 2013) and the second, Coproduction and collaboration (Stark *et al.*, 2020).

Whilst definitions and discussions of terminology will be discussed and critiqued in detail through this chapter, an introductory clarification of the surface level understandings will be provided to ensure meaning is clear. Citing's of methodology will be in reference to an epistemological position, whereas method will be focused upon the measurement tools or strategies enlisted to collect and evaluate data (Bryman, 1984). When referencing paradigms, this refers to the fundamental beliefs and position within the world and views of research, and within this, terms such as epistemology and ontology are encompassed (Denzin & Lincoln, 1994).

The research design and analytic frameworks for each phase will be introduced, with ethics and governance discussed to conclude this chapter.

### **3.2 Positionality and reflexivity**

It is important to acknowledge that most research involves some contact between the researcher and participants, often including a connection with the topic area (Davies, 2008). For example, the author of this thesis identifies their connection to the topic area through a reflective preamble at the start of this thesis. The depth and nature of this connection, described as the researcher's position, can influences decisions made throughout the research, as well as the results and outcomes (Denzin, 2012). Multiple roles and positions can coexist, with these encapsulating a range of paradigms which can overlap (Denzin, 2012). When utilising a qualitative approach, positionality and

reflexibility are considered essential in monitoring possible biases resulting from these positions (Lutterell, 2000). A reflective journal is suggested as one of the ways this can be done. Braun and Clarke (2006) describe how themes in research do not emerge fully formed, whilst acknowledging the role of data, researcher experience, subjectivity, and research questions in ascribing meaning that lead to themes being identified.

Through positioning, the researcher in this study is considered an 'insider' which should be acknowledged as influencing stakeholder's willingness to take part. Dwyer and Buckle (2009) view this position as beneficial in understanding and interpreting the phenomenon, something an 'outsider' would have more difficulty in achieving.

### **3.2.1 Researcher position**

Central to decisions made about research methods is the researcher's position, which can be described as positionality. This provides links between the context and the research population aiming to be studied (Burton, Brundrett & Jones, 2008). A researcher's positionality shapes their own works, as well as the way they understand, interpret and value others' literature (Bourke, 2014). Several factors can influence a researcher's position, with opinions being influenced by values and beliefs, for example, religion, gender, geographical location, culture, and personal experiences (Burton, Brundrett & Jones, 2008).

The importance of an alignment between methodological and the researcher's positions is due to risks associated when these are misaligned (Thomas *et al.*, 2017). Equally, the misunderstanding or inappropriate rationalisation of the epistemological position of a chosen methodology may risk it generating unfitting or inaccurate conclusions, leading to it being viewed as low-quality (Thomas *et al.*, 2017). The awareness of my own research position forms part of self-reflexivity, described as an ongoing self-analysis of decisions and choices made (Callaway, 1992).

### **3.3 Method versus methodology**

Methodology has been widely discussed, generating various definitions and explanations. For example, it can be defined as “a theory and analysis of how research should proceed” (Harding, 1987, p.2). Schwandt (2001) further describe it as analysing the assumptions procedures and principles of the approach used to investigate a given phenomenon. These include Denzin and Lincoln (2000) who use strategies of inquiry, and Creswell (1998) who has used traditions of inquiry. Overall, methodology focuses upon the justification for the methods which are used within research (Carter & Little, 2007). Within this study, positioning theory and the method of participation were utilised.

Methods meanwhile are the techniques used within research to gather evidence (Harding, 1987), which also includes the procedures and tools of research more broadly (Schwandt, 2001). They therefore can be viewed as the action taken within research (Carter & Little, 2007). In this study, this includes a scoping review method, a Foucauldian Discourse Analysis and qualitative coproduced workshop design.

Whilst methodology and method are two independent constructs, they are closely related to each other, as methodology justifies methods, resulting in data production which can be analysed (Carter & Little, 2007). Data collected and its analysis works towards generating knowledge, with epistemology shaping methodology and justifying the produced knowledge (Carter & Little, 2007).

### **3.4 Paradigm and Philosophical Overview**

#### **3.4.1 Selecting an approach**

Selecting an approach is a personal decision which is influenced by personal beliefs, and value placed on areas of importance. Such a framework is required to reflect personal beliefs and values within the specific research topic (Dash, 2005). Norton (1999, p.32) clearly defines one's methodological approach as being ‘how researchers go about finding out whatever it is they think can be know’, and whilst it may be considered dated, it provides an understandable explanation. Our own views of reality and the creations of knowledge are significant in assumptions and decisions made

whilst undertaking research, reinforcing the need for this to be made clear in this study (Everest, 2014).

In order establish and define a research framework, Dash (2005, p. 4) suggests four questions that were needing to be answered during the selection of a paradigm and methodology.

1. What is the nature or essence of the social phenomena being investigated?
2. Are social phenomena objective in nature or created by the human mind?
3. What are the bases of knowledge corresponding to the social reality, and how can knowledge be acquired and disseminated?
4. What is the relationship of an individual with her environment? Is she conditioned by the environment or is the environment created by her?

Whilst these questions present a linear trajectory, within this study they evolved and emerged throughout the three phases. In addition to the above questions, the awareness that one's own research is framed by several assumptions has been cited, with four key questions being cited (Arthur *et al.*, 2012, p.15), which are:

- 'Ontology: What is the form and nature of the social world?
- Epistemology: How can what is assumed to exist be known?
- Methodology: What procedure of logic should be followed?
- Methods: What techniques of data collection should be used?'

The questions outlined above relate to the three decisions Carter and Little (2007) describe as being central within qualitative research. Namely, deciding on an epistemological position, selecting a methodology, or combinations of methodologies, and finally selecting methods within the epistemological and methodological choices. The overall aim of these three decisions is to generate data that is best able to answer the research questions (Carter & Little, 2007). Within this study, each phase utilises a different method, or technique of data collection, with an underlying methodology supporting each. Ontological and epistemological views influenced these selections.

### 3.4.2 Importance of identifying a research approach

The predominant approach within a thesis was needed to produce rich data, providing an insight into experiences that could be used to construct meaning. Establishing a position and research approach is supported by the philosophical challenges of understanding the meaning of knowledge across disciplines (Perla & Parry, 2010). Methods and methodologies are fundamental in the decision-making processes throughout research, as they represent your philosophical positioning, including the worth associated with investigating various topics (Arthur *et al.*, 2012).

Key questions to be considered when identifying a research approach are outlined below (guided by Kawulich, 2012):

- Paradigm: what paradigm informs your methodology?
- Theoretical framework: What theories inform the choice of your research topic, the research questions you ask, the literature reviewed, data collection methods, analysis, and interpretation?
- Research approach: what research approach is called for, based on the research questions developed from the theoretical framework?
- Data collection: what types and sources of data might you be able to use to help answer your research questions? What are the best ways to collect data for your study? What assumptions guide the choice of selection of participants in the study, the setting of the study and the techniques of data collection?
- Data analysis: how does theory inform your approach to data analysis and interpretation?
- Ethics: what are the ethical considerations for your study, based on the paradigm, theoretical framework, research approach, data collection and analysis?
- Validity: by what and whose standards are the design, data collection, analysis and interpretation of research findings deemed valid and reliable?

Within this study, these questions were considered throughout in a number of ways. Examples include data analysis was influenced by positioning theory whilst utilising thematic analysis. Also, measures were implemented within each phase of this study to ensure validity and reliability, specifically, in the third phase, a second facilitator was

present to memo and provide validation of themes. Overall, the standards sought for this study were peer-review quality and within the scope of ethical approval within the institution. With the researchers unique position of being autistic, this was an essential element to consider and document within the different phases of this study. Through embedding reflection within this thesis, this position is established and defined to ensure clarity for the reader. This chapter seeks to provide a summary of these questions, with more focused consideration provided within the reporting of each phase.

### 3.4.3 Paradigms and world view

The 'basic set of beliefs that guide action' have been defined through several terms (Guba, 1990), including that of worldview (Creswell, 2014), paradigms (Lincoln, Lynham & Guba, 2011; Mertens, 2010) and research methodologies (Neuman, 2009). Irrespective of the lexicon chosen to describe the concept, they all share the definition focusing on a general philosophical orientation about the world and the perception of, and value placed on research (Creswell, 2014). Some factors which may influence one's world view or methodological preference include discipline preferences, supervisor or mentors' views and previous experiences of research (Creswell, 2014). Beliefs based on these factors are likely to influence methods and methodologies adopted, with four being widely discussed (Creswell, 2014).

<u>Post positivism</u>	<u>Constructivism</u>
<ul style="list-style-type: none"> <li>• <i>Determination</i></li> <li>• <i>Reductionism</i></li> <li>• <i>Empirical observation and measurement</i></li> <li>• <i>Theory verification</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>Understanding</i></li> <li>• <i>Multiple participant meaning</i></li> <li>• <i>Social and historical construction</i></li> <li>• <i>Theory generation</i></li> </ul>
<u>Transformative</u>	<u>Pragmatism</u>
<ul style="list-style-type: none"> <li>• <i>Political</i></li> <li>• <i>Power and justice oriented</i></li> <li>• <i>Collaborative</i></li> <li>• <i>Change-oriented</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>Consequences of actions</i></li> <li>• <i>Problem-centred</i></li> <li>• <i>Pluralistic</i></li> <li>• <i>Real-world practice oriented</i></li> </ul>

Table 4: The four commonly cited methodologies (Creswell, 2014, p.6).



Paradigms are considered an overarching philosophical or ideological stance, consisting of beliefs about the nature of the world (Rubin & Rubin, 2005). Within health research, paradigms form the fundamental assumptions that underpin knowledge that is produced (Broom & Willis, 2007). Morgan (2007, p.50) provide an additional description of paradigms, as “shared belief systems that influence the kinds of knowledge researchers seek and how they interpret the evidence they collect”. Paradigms involve a position being established, both in terms reality, known as ontology, and knowledge, known as epistemology (Kalof *et al.*, 2008; Saunders *et al.*, 2009). In sum, paradigms are the basic sets of beliefs “that guide action” (Guba, 1990, p.17).

Traditional principles of validity and rigour have been used to challenges the use of qualitative research approaches (Braun & Clarke, 2013). When situating qualitative and quantitative beliefs, it can often draw upon the perceived value of what is best, rather than acknowledging that research design is a spectrum of paradigms and underpinning frameworks that all can contribute knowledge (Silverman, 2014; Alasuutari, Bickman & Brannen, 2008). Overall, understanding the wider structures of research and perspectives enabled a clear position to be established that supported decisions made during the research process, for example, the data collection methods employed.

#### **3.4.4 Epistemology, Ontology and Axiology**

Epistemology is considered a description of the branch of philosophy concerned with theories of knowledge and debates surrounding what we know, and what we can know about society and the world around us (Swain, 2016). Specifically, in social research, epistemologically based questions emerge as we enquire and probe into the nature of knowledge produced through our research and investigations (Swain, 2016). Other scholars describe epistemology as studying the nature of knowledge and its justification (Schwandt, 2001), with epistemological issues focusing on the adequacy of that theory of knowledge and justification for it (Harding, 1987). Carter and Little (2007) summarise these descriptions and define epistemology as the justification of

knowledge. Within constructivism, social and cultural contexts are essential factors to be understood. The researchers position within some of the contexts which the participants inhabit, specifically being autistic and female, is considered advantageous and a natural fit with this epistemological position.

A researcher's epistemological position guides the construction of research questions and is a foundation of what knowledge is sought and viewed as adequate (Crotty, 1998). The position adopted may be influenced by several epistemological questions, including;

- The types of data viewed as legitimate and meaningful
- What data is viewed as trustworthy?
- Where are we positioned in regard to objective quantifiable measures being more legitimate than subjective or qualitative constructions?
- Do we identify an external, objective truth? (Crotty, 1998).

When engaging with and adopting a specific methodology, an understanding and appreciation of its epistemological foundations are important, and whilst this is widely accepted, it is rarely explicitly stated (Thomas, Lubarsky, Varpio, Durning & Young, 2019).

Viewing participants experiences as 'truth' aligns with the relativist epistemological position (Charmaz, 2000). This embeds itself within constructivist theory, through viewing the researcher as an actor in the data production process, working collaboratively to produce meaning or theory (Denzin & Lincoln, 2000). Being aware of societal influences and beliefs systems is heightened within the subject of this thesis, as they have the potential to marginalise groups of individuals with certain demographic characteristics (Hemmersley, 2008). Within this thesis, focusing upon autism, which influences communication and social interaction, ensuring that the design and approach does not present a barrier to participation was of vital importance. Identifying a focus on autistic teenage girls allowed for a targeted understanding of the experiences of this population, rather than a more generalised understanding that had the potential to reflect the subconscious biases and norms embedded among society.

Swain (2017) defines ontology as being the set of philosophical debates relating to the nature of being and the contents of the world around us. Specifically, in fields such as the social sciences, classic debates centre upon the nature of 'being' or 'existence', as well as the physical and psychological makeup of human beings (Swain, 2016, p. 65). Further definitions focus upon ontology being the 'nature of reality' and the construction of the social world (Ormston, Spencer, Bernard & Snape, 2014, p.4). Beliefs about whether there is one reality, or multiple that are socially constructed, can be understood as ontology (Patton, 2002; Kawlulich, 2012). The importance of identifying our own ontological position is due to the subsequent views we place on knowledge and truth, namely our epistemological position (Ormston, *et al.*, 2014). In addition, research investigations are composed and influenced by these beliefs and assumptions, which can be a result of experience, thoughts, learnt knowledge or actions (Blaikie, 2007). Within this study that considers autistic teenage girls' social worlds, it was important to highlight the researchers position as bringing personal experiences to the study.

Within health and related disciplines, other considerations present for researchers. These include the integrative versus interpretive knowledge syntheses, and axiological perspectives of studies cited in their content being produced (Bearman & Dawson, 2013; Kelly-Blake *et al.*, 2018). Definitions of axiology are not new, with Pole (1961) describing these simply as the study of values. In addition, axiological integrity has been defined as the ability to retain values in transferring, translating, or synthesising axiological evidence (Kelly-Blake *et al.*, 2018; Varpio & MacLeod, 2020). In this study, the role of the researchers values and positions is embedded through the preamble and reflections to ensure transparency.

### **3.5 This study**

Overall, the studies described in this thesis emerged through an iterative process, influenced by the themes identified and the wider societal events outside of the research (specifically, the coronavirus pandemic). Section 1.2 presents an overview of the phases, specifically, the change in direction as a result of the pandemic. The

table below provides a summary of the three interrelated phases to the study reported in this thesis, their design, data collection method and frameworks used in analysis. Further detail and discussion of each of the elements in the studies are included in the related chapter.

	Chapter	Design	Data collection	Data analysis
Phase 1 Scoping Review	4	Scoping review	Systematic searches of 4 online databases	Charting (Arksey & O'Malley, 2005) Thematic Analysis (Braun & Clarke, 2006)
Phase 2 Foucauldian Discourse Analysis	5	Discourse analysis	Systematic searches using an online database.	Discourse Analysis (Willig, 2013).
Phase 3 Empirical coproduction	6	Coproduction and collaboration with autistic and professional stakeholders	Three phases of online collaborative workshops and email contributions.	Positioning theory (Harre <i>et al.</i> , 2009) Thematic analysis (Braun & Clarke, 2006).

*Table 5: A summary of the phases in this thesis.*

### **3.6 Phase one: Scoping Review**

Within the scoping review, it was imperative that information of protocols and procedures followed in collecting primary data in articles, were available within the secondary data analysis (Clarke & Cossette, 2000; Smith, 2008; Smith *et al.*, 2011). Secondary data analysis is described as “analysis of data that was collected by someone else for another primary purpose” (Johnston, 2013, p.619). In addition, the same basic research principles that underline primary data collection are followed, through a process of inquiry with a systematic process (Johnston, 2013). In the

scoping review, this was utilised as an exercise, where procedures and evaluations were central to the method (Doolan & Froelicher, 2009). Furthermore, the researcher's epistemological beliefs will go towards shaping the way it is conducted (Thomas *et al.*, 2019). Whilst scoping reviews are not attributed to a specific epistemology, they are primarily aligned with labels of subjectivism (Crotty, 1998; Lincoln & Guba, 1985; Thomas *et al.*, 2019). Subjectivism rejects notions of there being a single truth to find and instead asserts individuals' role in constructing reality through their experiences, interactions with others and surroundings (Lincoln & Guba, 1985; Thomas *et al.*, 2019).

### **3.6.1 Data collection**

Similar to other secondary data analyses, the scoping review method encompasses how the researcher obtains, reviews, and interprets data, and how it facilitates meeting the research questions (Creswell, 2009). Data in this review was collected through structured searches of four databases to identify articles that met the inclusion criteria. As a result, this was secondary data being identified to undergo the stages of analysis. Data was collected by the author, with support from an academic support librarian.

### **3.6.2 Data analysis**

Within the scoping review, Braun and Clarke's (2005) thematic analysis was undertaken to explore the themes in the data. Additionally, charting and memoing was undertaken to enhance this methodology. Memoing including note making throughout the process, enabling coding of these to be undertaken.

## **3.7 Phase two: Foucauldian Discourse analysis**

Foucauldian discourse analysis does not aim to understand the "true" nature of a concept or phenomena, but rather how language constructs specific versions of it (Willig, 2013). In addition, it considers the social, psychological, and physical effects of discourse, and aims to produce knowledge of the construct we are within, the reasons it is that way, and the implications for us, for example our sense of self. Thus, FDA draws upon a social constructionist orientation.

The assumptions that FDA makes about the world is that there is not one view that can be desired, as variations exist that are constructed through practice and discourse. Though, this approach acknowledges that some views are more widely used and supported, which can result in them being viewed more favourably or as more plausible. These variations can rise and fall in popularity or dominance, as change and transformation underpin the social construction of reality. Language is viewed as something that subjects are constructed through, rather than represented by, in turn allowing for various interpretations to be made. The purpose and aim of FDA is to identify and map these interpretations, along with evaluating their consequences. Overall, it views discourse as fundamental in the construction of meaning, and that our subjective interpretations are influenced through language. When drawing attention to the concept of power, discourse can construct its objects. Further, the prevalence and accessibility of these subject positions can influence what is said, done and felt by individuals.

If one applies the Foucauldian perspective, all forms and knowledge are believed to be constructed through discourse and the related discursive practices, which can include specialist or scientific knowledge. This can be applied to the publications produced by researchers in that they are based around a specific framework. Therefore, being aware of, and able to reflect upon one's own knowledge, is an important part of FDA.

### **3.7.1 Data collection**

Drawing on understandings of secondary data analysis, in this phase the purpose of the original publication was identified where possible as well as the context in which they were published, for example, the wording used in the title or headline (Doolan & Froelicher, 2009; Magee *et al.*, 2006). Data in this review was collected through the online database, Lexis©. Specifically, searches identified newspaper publications from national UK publications that fulfilled the inclusion criteria, thus rendering this secondary data analysis. Whilst secondary data analysis is primarily found within research sectors, applications in news media can be established through the position offered by the author about the topic being studied. In addition, the availability of

contextual factors, such as the researchers goals when collecting data, as well as similarities and differences in the worldviews or positions of authors compared with one's own (Boslaugh, 2007; Stewart & Kamins, 1993).

### **3.7.2 Data analysis**

In the Foucauldian discourse analysis, the principles of discourse analysis as described in Charmaz (2014) were adopted. Additionally, positioning theory was enlisted to develop the analysis to unpick how discourse and discursive strategies position autistic teenage girls.

## **3.8 Phase three: Coproduction Empirical phase**

The empirical phase included within this thesis are fundamentally qualitative and conducted by a researcher (myself) whose ontological stance most closely aligns with constructionist definitions. This worldview considers social phenomena to be created from perceptions and actions of social actors, and therefore, their meanings evolve, and they are only static at the point in time that they were defined or constructed (Bryman, 2012). The philosophical beliefs that we hold regarding the nature of the world and how we enhance knowledge, has led to an array of positions and worldviews being defined. These can be explained as being on a continuum, with each providing different meanings ascribed to knowledge and research, as well as the way in which this knowledge is sought. This continuum views a positivist approach as being on one end, with interpretivist or pragmatic approached being at the alternative end.

### **3.8.1 Data collection**

Data in this phase encompassed two elements. The first was the written and verbal contributions of stakeholders through the online workshops and email communications. The second was the report co-created during the workshops. To reduce the possible disruption to data collection arising from coronavirus restrictions, an online method of data collection was selected. More detail about recruitment and sampling is included in section 6.3.

### 3.8.2 Data analysis

Positioning theory was the primary analysis tool adopted in the empirical phase. As the study enlisted a coproduction approach, thematic analysis was used to identify themes within each workshop and stakeholder group.

### 3.8.3 Stakeholders – who are they?

Stakeholder engagement is situated within an interpretive approach to priority setting (Pellicano, Dinsmore & Charman, 2014b). This approach focuses on the opinions of stakeholders, seeking these when making decisions (Lenaway *et al.*, 2006). Within health research, this approach has been utilised when identifying priorities (Lloyd & White, 2011; Oliver, Clarke-Jones & Rees, 2004), though Pellicano, Dinsmore and Charman (2014b) describes a limited use when focused on autism. Within an interpretive approach, active communication has been prioritised, encompassing engagement with knowledge users, researchers, and other stakeholders (Bowen & Graham, 2013; Illes *et al.*, 2010). Elsabbagh *et al.*, (2014) describe some of the stakeholder groups in autism research as autistic people, families, clinicians, educational professionals, and policy makers. Whilst stakeholders are involved, there is variability in when they become engaged with the research process (Roche, Adams & Clark, 2021). For example, most engagement can commence once the research questions have been established (Roche, Adams & Clark, 2021). This thesis is situated among a small proportion of research that has embedded stakeholder perspectives and opinions through the entire process (Jivraj *et al.*, 2014).

This thesis utilises the term ‘stakeholder’ to encapsulate groups identified by Elsabbagh *et al* (2014), with the added focus on females. Figure 2 highlights the groups previously identified and the refined categorisation within this thesis:

<b>Elsabbagh <i>et al</i> (2014)</b>	<b>This thesis</b>
Autistic people	→ Autistic females
Families	→ Families of autistic females
Clinicians	→ Clinicians with contact or involved with autistic females



Educational professionals	→	Educational professionals involved with autistic females
Policy makers	→	Policy makers involved with autistic females
	+	Wider professionals and third-sector organisations that provide support or a service for autistic females

*Figure 2: The stakeholder groups in this thesis, guided by Elsabbagh et al., (2014)*

The use of stakeholders and the categorisation of these can be primarily found in chapter six, a stakeholder coproduction phase.

### **3.9 Positioning theory**

Positioning theory contributes to understanding social action (Harre, Moghaddam, Cairnie, Rothbart & Sabat, 2009). It seeks to highlight explicit and implicit assumptions and beliefs ascribed towards others (Harre *et al.*, 2009). Falling within the domain of cognition, this theory contributes a moral domain, identified as practices and beliefs concerning duties and rights (Harre *et al.*, 2009). focusing upon interpersonal encounters, positioning theory identifies interconnected aspects, including:

- “Rights and duties are distributed among people in changing patterns as they engage in performing particular kinds of actions.
- These patterns are themselves the product of higher-order acts of positioning through which rights and duties to ascribe or resist positioning are distributed.
- Such actions are the meaningful components of storylines. Any encounter might develop along more than one storyline, and support more than one storyline evolving simultaneously.
- The meanings of people’s actions are social acts. The illocutionary force of any human action, if it has one as interpreted by the local community, determines its place in a storyline and is mutually thereby determined. Any action might carry one or more such meaning” (Harre *et al.*, 2009: 7-8).

Davies and Harre initially described positioning theory in 1990, however, the importance of this output transcends to the current day through its high number of citations, with it being the Journal for the Theory of Social Behaviour’s most frequently

cited publication (McVee, Silvestri, Schucker & Cun, 2021). This publication has been applied across a vast number of disciplines through theory, research, and practice (McVee *et al.*, 2021). Examples of these disciplines include social science, linguistics, education, and political studies (McVee *et al.*, 2019). The scope of positioning theory extends from conversational interactions to include policy documents, news media accounts and radio broadcasts (Löfdahl & Pérez Prieto, 2009; Montiel *et al.*, 2014; Rothbart & Bartlett, 2010). When exploring the dynamics of social life, positioning theory utilises positions, storylines, rights, and duties to underpin this. It should be noted that a position differs from a 'role', as positions evolve in response to social contexts whereas roles often being fixed (Harré & van Langenhove, 1991). Encompassed within the term 'position' is the diverse nature of human experience along with insight into a social order than is under constant change (Harré & van Langenhove, 1999).

Incorporated within positioning theory is the concept of power, as discursive positions draw on the rights to position oneself and others. Allocating discursive power informs understanding of 'social reality', as positions are features of the moral context embedded in the social world (Harré *et al.*, 2009). Using positioning theory as a research analysis tool may highlight embedded assumptions and stereotypes in areas of being, for example, within news media (van Langenhove & Harré, 1994). Positions evolve across intrapersonal, interpersonal and intergroup interactions to construct meaning, thus reinforcing the complexity of social reality (O'Connor, 2007).

Van Langenhove and Harré (1999) identify that three forces interact in positioning theory; position, storylines and social force. These forces are interrelated with them each impacting on the outcome in a given situation. Storylines provide the context and 'background' for positions to be presented and interactions to be made (Campbell & Lott, 2010). Positions bring with them expectations and a role within wider social and organisational networks, for example, by undertaking a research project, the researcher is positioned in a larger network of academics and collaborators (Campbell & Lott, 2010). Additionally, identifying positions can reveal how one constructs meaning, helping to make sense of their social world (O'Connor, 2007). Finally, social forces are the influences that are put on a situation or individual from the environment (Campbell & Lott, 2010).

As a result, this was considered a match to the focus of this thesis, where the experiences of autistic teenage girls were sought, focusing upon the social world (McVee, Silvestri, Schucker & Cun, 2021). Though utilising this approach, contributions will undoubtedly focus upon the subject area, however, McVee (2017) cite the importance of the wider contributions to the theory of positioning spanning multiple disciplines.

### **3.10 Method: participation and coproduction**

Participatory research has been discussed in literature for over twenty years, though there are strict bounds to this method (Bourke, 2009). This method positions participants as contributors involved in the research process (Macaulay *et al.*, 1999). In addition, the relationship between researcher and participant is a partnership, whereas more traditional methods view participants as subjects or content to be measured (Schwab & Syme, 1997). Critiques of this approach perceive there to be a lack of objectivity, reflective of a positivist paradigm (Bourke, 2009). Power and hierarchy are addressed in this approach, as participants are viewed as experts, with knowledge created a collaboration between them and the researchers, thus, removing the power associated with being the researcher (Campbell, 2002; Wahab, 2003). When considering the inclusion of service users in health research, Needham and Carr (2009) describe the most effective coproduction to include active participation within all decision-making levels. This view aligns with the desires and priorities of the autistic community (Ridout, 2016). Focusing upon the groups that often are considered to be marginalised, Björgvinsson, Ehn and Hillgren (2010) highlight a benefit of participation as empowering these individuals and groups. Chown *et al's.*, (2017) draft framework in conducting inclusive autism research was influential source, with its principles, such as the outputs having a direct benefit for autistic people being enlisted in this study. When engaging participatory or co-design approaches consideration should be given to the local context to ensure a fit between the intentions and purpose of the research to the aims and expectations of the stakeholders (Greenhalgh *et al.*, 2019). Within this, it is important to establish trust and allow for communication that is accessible for researchers and participants to ensure the process is meaningful and any outputs are authentically co-produced (Scott-Barrett, Cebula & Florian, 2019).

Further, meaningful participation requires the power dynamics between all involved to be identified and addressed from the start (Scott-Barrett, Cebula & Florian, 2019).

The positioning of participants as experts and the description of the relationship with the researcher highlighted it as a beneficial approach to adopt when conducting this study, with it being utilised in phase three (chapter six).

### **3.11 Discourse**

To introduce discourse, Fairclough's (2000) definition is presented, which describes how discourse refers to the variety of methods of knowledge creation and its structure. Punch (2000) presents discourse as the way language is used, its purpose and context, rather than its semantic structure. Theoretical understandings and assumptions of discourse highlight its role in learning and knowledge processes (Lefstein, Louie, Segal & Becher, 2020). Furthermore, it can be viewed as essential when making meaning, defining roles and negotiating identities (Barton & Tusting, 2005). Foucault (1991) highlights how discourse presents a view on the world, positioning that as knowledge and the reality, thus acting as an instrument of power. Moreover, discourse contributes to knowledge creation, with language reflecting the emerging social and cultural changes (Fairclough, 2000). Synthesising the above discussions, Melville-Richards (2015, p.100) describes how discourse encompasses a wider documentary perspective, in which 'ideas and meanings are formulated, transmitted, and negotiated through multidimensional modes of communication and shared understanding'.

### **3.12 Comparative approaches**

#### **3.12.1 Constructionism**

Constructionism can be explained as viewing lived experiences as being in the mind, with factors such as language and discourse offering varying perspectives of that reality (Kazi, 2000). Specifically, Kazi (2003, p.13) cite the constructionist belief that 'there is no reality which can be used as a standard, and that there are therefore many truths which are all equally true even if they are contradictory'. The stakeholder perspective within the constructivist approach outlines there being multiple realities

based upon interpretations and perceptions of the group of individuals being considered (Alkin & Christie, 2004). Essentially, this represents the view of reality being socially constructed and fundamentally specific to every circumstance and situation (Bergin *et al.*, 2008). Stake (1995, p.100) describe how at various life stages, understanding comes from experiences and 'being told what the world is'.

Swain (2017) outlines similar definitions of constructivism, which focus upon three key understandings. The first focuses upon meaning being 'multiplicitous and dependent on context', the second that factors are not independent from our views, but interpreted through our own prior experiences, and the third that research should try and understand a concept or phenomenon from the subject's point of view, not one's own beliefs (Swain, 2017, p.63). Within constructionism, there are various stances, for example rationalist-constructivists and post-positive constructionists (Parahoo, 2006; Bhaskar, 1979; Wilson & McCormack, 2006). The former conflicts with the positive aim of seeking truth, whereas post-positive approaches present descriptions in a more understandable way (Parahoo, 2006; Wilson & McCormack, 2006).

Beliefs of what is reality are driven by social constructs, which can therefore contain many realities (Creswell, 2003; Mertens, 2009). The assumptions forming this approach legitimise concepts and understandings from all cultures and societies, in addition to recognising both individual and group-shared realities (Kawulich, 2012). The main purpose of this approach is to understand people's experiences, which as a result, typically enlists data to be collected within a natural setting. The basis and reasoning for the research taking place is driven by the researchers desire to understand human experiences. This approach also provides reassurance that having research questions that evolve during the study progression is fitting to the overall paradigm (Mertens, 2009). In addition, these questions are open ended, descriptive and without a hypothesis to be tested (Creswell, 2003).

### **3.12.2 Grounded Theory and its variations**

The grounded theory method focuses on the aim of theory construction which represents the specific group of people included in the study (Charmaz & Belgrave, 2019). This utilises rigorous analysis and data conceptualisation, as well as modelling

an iterative and interactive method (Charmaz & Belgrave, 2019). As a result, data gathered through grounded theory methods evolves throughout the study, with a range of possible understandings remaining present to ensure it is the best fit for the data (Charmaz & Belgrave, 2019). Highlighted by Glaser and Strauss (1967), grounded theory avoids the influence of a pre-determined theory when collecting data, allowing theory to emerge naturally (Amesteus, 2014). This definition and understanding are generally agreed upon whichever variation of the theory is adopted (Charmaz & Bryant, 2011), though each diverges in their view of the data. Specifically, constructivist grounded theory outlines a view of data being co-constructed, and located within the researchers and participants social, historical, and situational environments (Charmaz & Belgrave, 2019). Researcher reflexivity is important, specifically examining our own values, beliefs, and actions (Charmaz, 2017b). In addition, developing our methodological self-consciousness includes examinations of our position or positionality (Clarke, 2005; Clarke, Friese & Washburn, 2015).

Objectivist grounded theory takes a realist stance, with data being the source to achieve a wider goal of conceptualisation (Glaser & Strauss, 1967). In addition, Glaser (2001) extends this view, treating data as resources to form into theoretical categories, detached from people, time and place. Specifically, objectivists see data as separate and detached from researchers and observers (Clarke, 2005; Flick, 2019). A definition provided by Arthur *et al.*, (2012) cites grounded theory as being a qualitative and inductive approach, designed with the aim of exploring, analysing, and generating concepts about actions or social processes. Grounded theory approaches centre on flexible guidelines for data collection, with a focus on allowing theories to be constructed from the data collected (Charmaz, 2014). Nonetheless, it still offers systematic guidelines to support in the collection and analysis of data (Arthur *et al.*, 2012). In addition to this, guidance for using this approach focus on general principles, guidelines, and strategy, rather than a prescribed set of actions and rigid structural guidance (Atkinson, Coffey & Delamont, 2003).

The addition of the constructivist element to this theory increases focus upon inductive, comparative, emergent and open-end approach from Glaser and Strauss's initial recorded definition in 1967 (Glaser & Strauss, 1967; Charmaz, 2014). The constructionist view of grounded theory allows for more than asking and learning how

people view a specific situation of phenomena (Bryant, 2002). Theoretical stances developed through research using this approach include review of participants contributions, and are acknowledged as being one researchers' interpretation, therefore cannot be applied to broader contexts (Bryant, 2002; Charmaz, 2000, 2002). For researchers adopting this approach, there is a shared understanding that data analysis are social constructs reflecting the specific processes used and decisions made (Bryant, 2003; Hall & Callery, 2001; Thorne, Jensen, Kearney, Noblit & Sandelowski, 2004). In grounded theory, the researcher is conceptualised as a variable that should be considered, whereas the researcher is viewed as central in CGT (Glasser, 2002).

This view of grounded theory allows researchers to concentrate what currently is featuring in the field, identify they are part of that field, but remaining flexible and aware of developments to bring research into public domains (Charmaz, 2020). Learning about the challenges or experiences of the population being studied is important, with CGT allowing for practical problems to be addressed in addition to promoting social justice (Charmaz, 2017b). A willingness to delve beyond the obvious or convenient explanation for a phenomenon enhances the reflective processes, as well as encouraging new insights and early formed concepts to emerge (Locke, Golden-Biddle & Feldman, 2008). The iterative nature and processes within CGT allow for surprising or unexpected findings to be followed up, and compared to other views of grounded theory, ensures that this is considered within its social, historical, political, and situational contexts (Charmaz, 2020). This requires skill in ensuring that these do not influence or encourage a reproduction of these views, with it being important also that whilst we acknowledge the learning from participants, we cannot claim to know what they feel and how they experience the world (Murphy & Dingwall, 2003).

Specifically, this approach allows for the focus to remain on the phenomena being studied, as well as data and analysis being considered a shared and collaborative process built on the established relationship between all involved (Charmaz, 1990, 2000, 2001; Charmaz & Mitchell, 1996).

### **3.12.3 Phenomenology**

Primarily, phenomenology focuses upon human experience, specifically those that are 'pure, basic, and raw in the sense that they have not (yet) been subjected to processes of analysis and theorising...' (Denscombe, 2014, p.95). Further guidance of topics which may be suited to this approach include investigations of people's perceptions, meanings, attitudes, and beliefs, and feeling and emotions (Denscombe, 2014). This methodological approach focuses on an individual's experience of existence, often through interpretations of text and narrative discourse (Mackey, 2005). The epistemological assumption that language is key in understanding experience presents in phenomenology (Newman, Cashin & Waters, 2010). Neurotypical individuals can retrieve stored information to unify knowledge about the world, with experiences constructed through these and expansions of this knowledge (Cashin, 2005). Variations in cognitive processing styles in autistic individuals may be appear opposed to principles of phenomenology (Newman, Cashin & Walters, 2010).

### **3.12.4 Realism**

Realism focuses upon the understanding that what happens in the world is independent from our understanding (Swain, 2017). This approach in both social and 'hard sciences' aims to have an objective view of the topic of study, separate from own and theoretical descriptions of the phenomena (Swain, 2017, p.68). This approach denotes the value of explanation, whether that be for a behaviour or relationship between two concepts or structures (Porter, 2001). Westthrop *et al.*, (2011) extend this definition and cite that within realism, there is an overriding belief and awareness of the various systems present in the world, for example, social, psychological, and material. A belief in the existence of theoretical constructs is required to fully embrace realist methodology (Williams, 2013).

## **3.13 Ethical considerations and governance**

All phases of this study were presented to Bangor University Ethics Committee at the level appropriate to the design. The co-produced phase (chapter 6) required a full submission as it involved stakeholders, but as it was not recruiting through the NHS it was not required to be submitted to the NHS R&D Office (see appendix 35 for ethical approval). Due to a limited initial success with recruitment for the empirical phase, a



subsequent amendment application was submitted and granted to expand the geographical inclusion criteria for stakeholders.

The protocol as approved by the ethics committee was always adhered to. The researcher obtained a DBS check prior to commencing the studies.

### **3.13.1 Language for conducting the research**

For the phase described in chapter six, all material and documentation were provided bilingually in Cymraeg and English to all stakeholders. As the researcher was not a fluent Welsh speaker, the workshops were conducted in English. Translation was completed by the University's translation department, Canolfan Bedwyr, to act as quality assurance.

### **3.14 Chapter three summary**

This chapter presents the overall method and methodology enlisted within this thesis. Specifically, the position of the researcher and underlying worldview that influenced decisions made throughout the research journey. It also introduces the three phases, their overall approach, data collection methods and analysis frameworks.

## **Chapter 4: Phase one**

### **AUTISTIC TEENAGE GIRLS AND THEIR SOCIAL WORLDS: A SCOPING REVIEW**

#### **4.1 Introduction**

This chapter is a scoping review of academic journals relating to autism in teenage girls published between 1999 and 2019. A scoping review guided by Arksey and O'Malley (2005) was chosen to identify gaps and the topics covered in previous research, drawing on the background literature highlighted in chapter two. Chapter two shaped the focus of this scoping phase, which subsequently refines the contributions of academic research to the social discourse of autism for autistic teenage girls.

This chapter will discuss the reasons for selecting this approach, present the steps taken to complete the scoping research and its findings. In presenting the findings, seven themes surfaced across the data through the use of thematic analysis. Chapter three first introduces the scoping review method, its design and analysis, with this chapter utilising the twenty-seven items on the PRISMA-ScR to structure the narrative (Tricco *et al.*, 2018).

#### **4.2 Scoping Review: Aims**

Within this scoping review phase, two levels of aims can be identified. First, as outlined in section 1.2.1, there are several aims embedded throughout the thesis. Aims two and three are specifically pertinent within the scoping review, and as such, are presented below:

- Aim 2: To identify the topics and concepts of important consideration for this group (autistic teenage girls).
- Aim 3: To gain an understanding of how autistic teenage girls navigate their social worlds.

Secondly, through the scoping review process of identifying research questions, seven aims specific to this phase were identified. This process is discussed further in section 4.4.5.2.

### **4.3 Previous literature**

Following on from the topics discussed in Chapter 2, this section provides a synopsis of the previous research relating to autistic teenage girls and their social worlds, underpinned by considerations of mental health and well-being.

#### **4.3.1 Autism and gender**

The study of autism and gender is limited in frequency and demonstrates a preference for second hand or quantitative based data collection methods, i.e., teacher reports and observations. (Fulton *et al.*, 2017). Furthermore, gender is rarely the primary consideration and focus of the research (Baron-Cohen *et al.*, 2011; Fulton *et al.*, 2017; Lai *et al.*, 2013; Sipes *et al.*, 2011). In addition to this, the focus on female participants has only recently started to increase. McPartland and Volkmar (2013) suggest that this is due to the predominance of autistic males and males being diagnosed as autistic, meaning this group was more readily available for research.

As this is an area limited in research, it may be expected that it is a more recent area of knowledge emerging, however, this is not the case (Lai *et al.*, 2015; Baron-Cohen *et al.*, 2011). With scholars discussing the effect of gender and the possible male bias within autism in the early 1980s, it is astounding that it is still an area with limited research exploration (Tsai, Stewart & August, 1981; Lord, Schopler & Revicki, 1982; Wing, 1981a; 1984). Whilst this review will not cover the full time between initial discussions and the current day, it aims to provide a deeper understanding of the research direction and what we can learn from it. The focus on adolescence stems from the limited research beyond the early years, in addition to this being viewed as a life stage with increasing social complexity. The focus on the social experiences and social world is a result of this being identified in the literature review as an area specifically pertinent to autistic females.

#### **4.3.2 Autism and adolescence**

Developmentally, adolescence is a critical period of development that is considered a bridge between the boundaries of childhood and adulthood (Aggarwal & Angus, 2015;

Leonard, 2016; Prout, 2005). Focusing upon this population is a result of awareness that adolescence is a time of increased change for young people, as well as one which presents increasing levels of complexity within social interactions, social relationships, and social expectations (Seifert, Hoffnung & Hoffnung, 2000). The change and increase in complexity are more prevalent in female populations, as well as being more intense (Foggo & Webster, 2017; Moyse & Porter, 2015). Adolescence is a period where intimate relationships and friendships are increasingly important and is linked with protective factors of well-being for females (Masten, Telzer, Fuligni, Lieberman, & Eisenberger, 2012; Mazurek & Kanne, 2010; Waldrup, Malcolm, & Jensen-Campbell, 2008). This brings an increased challenge and intensity for autistic females, due to difficulties with social pressures and the desire to comply with the complex and evolving social standards (Foggo & Webster, 2017; Landa & Goldberg, 2005; Moyse & Porter, 2015).

#### **4.3.3 Autism and social experiences**

Social competence in interaction and communication has been identified as an area of difficulty frequently presenting in autistic individuals (Chevallier *et al.*, 2012). This considered, research focused upon female populations suggests there is an increased likelihood of such difficulties being managed through concealing difficulties and developing strategies to overcome barriers experienced (Solomon *et al.*, 2012). The navigation of social change and difficulties during adolescence has been postulated as a significant factor in the higher rates of mental health diagnoses in autistic females (Chan & John, 2012; Cottenceau *et al.*, 2012; Rivet & Matson, 2011a; Seltzer *et al.*, 2004; Solomon *et al.*, 2012; William *et al.*, 2012). Explanations for this include the increased time spent socialising with peers, as well as the perceived importance of fitting in. As a result, the topics of social change, adolescence, and mental health were included in the search terms, and provided a focus for the aims of this review.

Challenges within friendships and social relationships are heightened in the period of adolescence (Bargiela *et al.*, 2016). Although, due to the complexity of conceptualising friendship, challenges may go undetected, as females are more typically ignored rather than being clearly excluded within a group or activity (Bargiela *et al.*, 2016; Dean *et al.*, 2014). Within diagnostic assessments, an

exploration of friendships should encompass understanding of the gender differences, as well as considering friendship as a complex and variable concept (Bargelia *et al.*, 2016; Hartley & Sikora, 2009).

Whilst primarily focused upon the misdiagnosis of autism, Lai and Baron-Cohen (2015) document the overlapping features of autism and mental health conditions, which within the context of this study, supports the need for an understanding of the effects of social navigation. Through such links between autism and mental health difficulties, establishing the methods and consequences of social navigation aims to increase the awareness and understanding of external and internalised effects, for example on mental health. Camouflaging or masking may present an explanation for this.

An awareness of camouflaging or masking difficulties has been explored in previous studies of autism, with there being an accepted difference between externally displayed behaviours, internal processing, and true effects (Gould, 2017). Camouflaging within the field of autism is defined as using strategies to limit the visibility of it within social situations (Lai *et al.*, 2011). This can involve a specific effort to mask or compensate for autistic characteristics through conscious and unconscious techniques, for example, forcing oneself to appear to be making eye contact (Hull *et al.*, 2017; Lai *et al.*, 2017; Livingston & Happe, 2017). Furthermore, the use and ability to use this strategy is considered higher in female populations (Dean, Harwood & Kasari, 2017; Lai *et al.*, 2017). The possible detriment of enlisting this mechanism is supported by the increased risk of autistic individuals receiving a diagnosis of a mental health condition (Ay-Yeung *et al.*, 2018). A more in-depth discussion can be found in section 2.7.6.

The rapid growth and prominence of the internet and social media has been explored in the general population, with daily engagement levels of around 60% of users being obtained in samples of typically developing individuals and those with additional needs (Olafsson, Livingstone, & Haddon, 2013; Livingstone *et al.*, 2011; Del-Manso *et al.*, 2011; Didden *et al.*, 2009). The importance and need to consider this development is supported by an awareness that internet and social media usage has and continues to change the ways we communicate (Abel, Machin & Brownlow, 2010).

#### **4.3.4 Summary**

Whilst literature has been identified, there remain gaps in the reasons for the outcome being discussed, for example, reasons for the variation in presentations. In addition, there are limited suggestions of how findings influence actions in the real world, including the role of participation with autistic people.

Overall, the synthesis provided above outlines the key topics extracted from the broader narrative review that was conducted (Chapter 2). These therefore are important considerations through the design and data collection stages of the review. The use of a rigorous methodology to explore these topic areas will result a more comprehensive awareness and understanding of this topic area. In conclusion, these themes provide a starting point that a review can build upon.

#### **4.4 Method**

Within any research study, it is important to be familiar with existing literature and key debates that underpin the topic area (Grant & Booth, 2009). Specifically, within healthcare, being familiar with the literature helps to map evidence, thus driving forward understanding through an incremental staged approach to data collection (Gagliardi & Alhabib, 2015; Rumrill, Fitzgerald & Merchand, 2010). Collating, evaluating, and presenting evidence are essential components of research, with reviews of literature being an enabling factor in these being achieved (Arksey & O'Malley, 2005). With a variety of approaches available to researchers, there can be challenges when collating literature to facilitate decision making, specifically if inconsistencies and variations in terminology exist (Cronin, Ryan & Coughlan, 2008).

Traditional types of literature reviews are available to utilise include systematic reviews, literature reviews, and meta-analysis (Arksey & O'Malley, 2005). These review types have variations in their design, structure, and underlying assumptions, which allow for them to be distinguishable from each other (Grant & Booth, 2009). Selecting the most appropriate method can be complex, as some reviews align more closely with some

research questions, such as those that are qualitative or quantitative, with no single review type fitting all types of study (Kastner *et al.*, 2012).

#### **4.4.1 Approaches to literature review**

##### **4.4.1.1 Systematic review**

A systematic review is defined as a detailed and comprehensive methodology with the ability to provide a synthesis of literature (Uman, 2011). It does not seek to create knowledge, therefore there is the requirement for relevant research to have been conducted (Averis & Pearson, 2003; The Joanna Briggs Institute, 2001). Examples of the use of these are in investigations of intervention effectiveness and treatment efficiency, although, they may not always be as effective in explaining differences because of context, such as the setting of delivery (Pawson, Greenhalgh, Harvey & Walshe, 2005). Standardised processes feature in systematic reviews, including the search for evidence, appraisal, and a subsequent synthesis of the findings (Ferrari, 2015). Furthermore, systematic reviews analyse the data extracted from included research articles (Aromataris & Pearson, 2014). These methods are clearly defined prior to commencing the review, resulting in transparency and additional consistency to allow for future replication (Grant & Booth, 2009).

Limitations of this approach have been discussed, such as challenges in reviewing all evidence, that results in uncertainty on its implications (Dixon-Woods, Agarwal, Jones, Young & Sutton, 2005). With a clear research question, this type of review is useful in exploring data from quantitative based studies, and more recently, this has expanded to include qualitative evidence (Gough, Thomas & Oliver, 2012). Through attempts to include all evidence and data appropriate to the research question, systematic reviews are limited in their consideration of overarching concepts or theories (Averis & Pearson, 2003; Higgins *et al.*, 2021). However, in the present study, there was no clearly defined topic and question aiming to be answered, and thus this approach was deemed unsuitable (Davis *et al.*, 2009). Whilst an evaluation of the quality of the literature would be a consideration, the primary purpose of a review in the context of the present thesis was to summarise previous works which had been completed,

whether there were any gaps, and where future research should be directed (Davis *et al.*, 2009).

#### **4.4.1.2 Scoping review**

Whilst definitions of scoping reviews may vary, at a general level, they aim to map key concepts that underpin a research area and the evidence and sources that are available (Anderson, Allen, Peckham & Goodwin, 2008; Arksey & O'Malley, 2005; Davis, Dray & Gould, 2009). In addition, scoping reviews can be viewed as a method of data collection. Four reasons for undertaking a scoping review are detailed by Arksey and O'Malley (2005), with the fourth being most applicable in this review:

*“To identify research gaps in the existing literature: this type of scoping study takes the process of dissemination one step further by drawing conclusions from existing literature regarding the overall state of research activity. Specifically designed to identify gaps in the evidence base where no research has been conducted, the study may also summarize and disseminate research findings as well as identify the relevance of full systematic review in specific areas of inquiry” (Arksey & O'Malley, 2005, p.21).*

Scoping reviews use a strong, rigorous, and transparent methodological framework to explore a complex or multi-dimensional concepts or questions (Arksey & O'Malley, 2005). In addition, they enlist an iterative, rather than linear process, which requires engagement throughout the stages and reflexivity to ensure literature is covered comprehensively (Arksey & O'Malley, 2005). They are useful to identify where the gaps are in current literature, as well as directing future research (Tint & Weiss, 2016).

The validity of this approach, as well as several citing's of its uses within healthcare domains supports its use for this topic (Munn *et al.*, 2018; Pham *et al.*, 2014). Credit for the scoping review method stems from its ability to explore both established and developing fields of study (Colquhoun *et al.*, 2014). In addition, due to the relative emergence of the field of study, the selection of the approach was reinforced (Armstrong *et al.*, 2011). The identification of gaps in previous research



extends to the methodological approaches used, to inform future study design. This again has been identified as one of the purposes and justifications for the use of a scoping review (Munn *et al.*, 2018). Whilst specific research questions had been identified, the broad nature of the topic area was considered suited to the methodological framework and synthesis associated with scoping reviews (Peters *et al.*, 2015).

#### **4.4.2 Rationale for choosing the Scoping review approach.**

Scoping reviews are a more recent development in the field of review, following on from thematic and systematic reviews (Munn *et al.*, 2018; Grant & Booth, 2009). Scoping and thematic reviews share various similarities, namely that they both follow a structured process (Arksey & O'Malley, 2005; Peters *et al.*, 2015; Levac, Colquhoun & O'Brein, 2010). However, there are differences in their methodology as well as the aims of conducting the reviews (Arksey & O'Malley, 2005; Peters *et al.*, 2015; Levac, Colquhoun & O'Brein, 2010).

Some of the differences between scoping review and systematic review are the purpose that informs the review taking place. Systematic reviews follow a pre-defined structure to produce reliable findings which can be applied to a research question or hypothesis, as well as informing further study and policy (Pearson, 2004; Aromataris & Pearson, 2014; Liberati *et al.*, 2009; Higgins & Green, 2011). On the other hand, scoping reviews help to discover the body of literature in an area, with the aim of mapping or outlining prior research and evaluations of that, for example, the methodological approach adopted (Arksey & O'Malley, 2005; Anderson, Allen, Peckham & Goodwin, 2008). Another different between these types of review is their breadth and areas of consideration. Scoping reviews will have a wider "scope" than a systematic review, and within this, a more expansive inclusion criterion (Peters, 2016). These types of review are inherently linked, as Munn *et al.*, (2018) describes how scoping reviews can be conducted as a precursor to a systematic review. Though, this does not limit their individual ability to fulfil a purpose and provide a rigorous framework to meet the aims of a given review.

The selected approach to review was considered the most appropriate method as the scope and clarity of the field of study drew upon various disciplines and fields of study (Levac, Colquhoun & O'Brein, 2010; Arksey & O'Malley, 2005; Rumrill, Fitzgerald & Merchant, 2010; Grant & Booth, 2009; Brien *et al.*, 2010; Armstrong *et al.*, 2011; Daudt, Van Mossel & Scott, 2013). This type of review also enables researchers to map and identify previous publications, to identify gaps and areas where more research may be beneficial (Arksey & O'Malley, 2005; Anderson *et al.*, 2008). A specific consideration within a scoping review is the type of evidence and results gained from previous literature and the methodologies enlisted (Bragge *et al.*, 2011). Again, this can be used to enhance the mapping of previous research.

#### **4.4.3 Quality appraisal**

Quality appraisal can be defined as the process of *'evaluating a research article carefully and systematically to determine the reliability, validity and application in clinical practice...we decide a research article is reliable or not...'* (Abdullah & Firmansyah, 2012, p.338). To conduct an appraisal, researchers have a broad selection of tools to draw upon (Katrak, Bialocerkowski, Massy-Westropp, Kumar & Grimmer, 2004). Though, there is a lack of consensus about which tool should be viewed as 'gold standard; (Katrak *et al.*, 2004). Scoping reviews do not aim to generate a critically appraised response to the question being asked, as their focus is upon providing an overview of the literature in a given field or topic area (Munn *et al.*, 2018). As a result, a critical appraisal of articles, including assessing the method, concerns around validity and reliability, are generally not conducted within scoping reviews (Aromataris & Pearson, 2014; Liberati *et al.*, 2009; Pearson, 2004).

Through a consideration of the limitations versus possible benefits of enlisting a critical appraisal, the decision to enlist the scoping review approach, which did not have the requirement of conducting quality appraisals on articles before being included, was reinforced as being the most appropriate (Levac, Colquhoun & O'Brein, 2010; Arksey & O'Malley, 2005; Rumrill, Fitzgerald & Merchant, 2010; Grant & Booth, 2009; Brien *et al.*, 2010; Armstrong *et al.*, 2011; Daudt, Van Mossel & Scott, 2013). Through the aims associated with a scoping review, namely mapping rapidly key concepts that underpin a complex topic

area, not including a critical appraisal allowed for quicker progress through data collection and sifting stages (Anderson *et al.*, 2008). As a result, this allowed for a more in-depth overview and analysis of the subject area (Anderson *et al.*, 2008; Mays *et al.*, 2001).

#### **4.4.4 Scoping review method.**

##### **4.4.4.1 Introduction**

Arksey and O'Malley (2005) outlined six stages when conducting a scoping review: identifying the research question, identifying relevant studies, study selection, charting the data, collating, summarising, and reporting the results, and consultation. The sixth optional stage, consultation, was not utilised as wider community engagement was planned for the empirical phase. Levac *et al.*, (2010) contributed to discussions about scoping review methodology and proposed some recommendations for scoping review when reflecting upon Arksey and O'Malley's (2005) framework. These five stages (Arksey & O'Malley, 2005) provided an outline of the steps taken to conduct the review, as well as being enhanced by Levac *et al.*'s., (2010) recommendations.

For this section, the methodology enlisted will be discussed in detail. It is primarily shaped by the PRISMA-ScR checklist, as this is a clear way of presenting methods in scoping reviews (Tricco *et al.*, 2018). Prior to the final methodology being confirmed, the checklist was used to form a protocol for the review, which outline the details and proposed methodological design (Tricco *et al.*, 2018).

##### **4.4.4.2 PRISMA-ScR**

The checklist is formed of twenty-seven items, which are considered in relation to this review in the table below (table 6) (Tricco *et al.*, 2018). Its primary purpose was to ensure that all aspects and requirements of the review were considered and executed.

Item number	Within this review
1	The paper was identified in the early staged of planning as a scoping review.

2	A structured summary was provided through the abstract of the review. Prior to this, a consideration of what would be included in it was described during the protocol and planning phases.
3	Questions for this review were identified, as well as identifying the method as appropriate. Previous findings within the field were discussed and considered to guide the search sequences that would be included.
4	Questions and objectives were defined, namely, to synthesise the previous literature in navigating the social world in female adolescents with a diagnosis of autism.
5	The protocol for this review was designed and evaluated with the project supervisors. In addition, details were submitted to the ethical committee to justify the completion of the project.
6	Eligibility for inclusion was clear. Namely that articles were found from one of the databases through the search sequences (or search for grey literature), in the English language and between 1 <sup>st</sup> January 1999 and 31 <sup>st</sup> March 2019 .
7	Information sources comprised four databases: ProQuest Social Science Collection, ERIC, PsychInfo and Springer.
8	The full search sequences were defined and standardised prior to collection through each database (see appendix 1 for full list).
9	Screening for inclusion was in six stages and is outlined in further detail in section 4.4.7.1
10	Charting was primarily done via data extraction to an excel document. The categories of data to be extracted were decided prior to data collection.
11	Data variables accounted for the large number of search sequences. Five variations of the identifier for autism were used. Similarly, other identifiers consisted of several variations.
12	A critical appraisal of sources prior to inclusion was not included within this review. However, such appraisal may have featured within the limitations identified in the articles.
13	Summary measures are not applicable for a scoping review.

14	Handling of results was through extracting the desired information from each article in turn. In addition, data was summarised through the identification of themes using Braun and Clarke's thematic review framework.
15	The risk of bias across studies is not applicable in scoping reviews.
16	Additional analysis is not applicable in scoping reviews.
17	13115 articles were obtained through data collection. Once duplicates were removed, and the stages of data sifting were completed, a total of 29 articles were included in the review.
18	Characteristics of data obtained were measured through the themes identified in the excel document prior to data collection.
19	Not applicable as critical appraisal was not part of the review.
20	The aims and objectives of each article were extracted, as well as the key findings and outcomes described by the authors.
21	A range of charts, graphs and tables were used to present the themes identified in analysis.
22	The risk of bias across studies is not applicable for scoping review.
23	Additional analysis is not applicable for scoping review.
24	The main results and findings are summarised in the results section of this review.
25	Limitations were cited of the scoping review method. Namely, in this study, a lack of multi-level agreement in decisions made.
26	Conclusions focused upon the main themes identified. These are discussed further within results and discussion sections of the review.
27	No funding was provided for the review and there were no conflicts of interests.

*Table 6: The areas of the checklist within this review.*

#### **4.4.5 Stage 1: Identify the research question.**

Within the framework stage 1, identifying the research question, Levac *et al.*, (2010) cites the relationship between the rationale for conducting the scoping review in

clarifying its purpose, as well as considering the population, concept, and context of the study (Arksey & O'Malley, 2005).

#### **4.4.5.1 Purpose of scoping review**

The purpose of the scoping review presented in this thesis was to identify issues and themes within current research exploring the social world of autistic female adolescents. In addition, it aimed to gain an understanding of what would be included within the term 'social world'. For the purposes of this phase and the search terms included, several key areas were chosen, which included friendships, relationships, social communication, social media and technology, social interaction, and social norms. These had been identified through the literature review and the researcher's previous studies in the topic area. Overall, the use of a scoping review method mirrors Levac *et al's* (2010) discussions of their ability to clarify complex topics and help refine subsequent research.

#### **4.4.5.2 Research questions**

The research questions for this review were derived from the aims (see sections 1.2.1 and 4.2), in that they address various elements within the more general aims. The importance of establishing research questions and objectives early within the scoping review method is supported by an awareness that without these, difficulties can emerge in later stages of analysis (Peters, 2016). As a result of this, a protocol for the phase was written and evaluated with two senior lecturers to ensure that the methodology was appropriate and that the aims questions were clear. Through this process, clear research questions were established based upon the topic area of autistic teenage girls' experiences of the social world. These were:

1. What themes are identifiable in the articles collected?
2. How does this review and its findings influence and shape the PhD more broadly?
3. What methodological designs are used in the articles, and how were they justified?
4. What samples are used in the published research? Can any themes or links to the methodological design be identified?

5. Are there any gaps in the research? For example, in the design, sample, or specific topic area.
6. How do the findings contribute to overall understanding and conceptualisation of the topic area?
7. What do the findings add to understandings of autistic teenage girls' experiences of the social world?

#### **4.4.5.3 Refinement of research questions**

During the design process, time was allocated to the research questions to ensure that they were appropriate to the topic area and applicable within the search sequences. As this scoping review aimed to refine the thesis, questions remained open and flexible towards the data collected. The overarching topic area was defined, providing a context for the specific questions outlined. The terminology utilised to refer to the sample, autistic people, within this thesis is discussed in detail in chapter one. Nonetheless, alternative terminology, such as Asperger's and ASD were included in the search sequences to ensure that relevant articles were not excluded based upon the language choice at the time of publication. Invariably, terminology as changed over time due to societal and academic developments, an example being the two updates to the main diagnostic criteria within the identified time (APA, 2000, 2013). The definition of the social world took on terms and concepts described in prior reading, as well as diagnostic criteria (APA, 2013).

In addition, the purpose for conducting the review was a significant consideration in the planning process. As the scoping review forms part of a larger project, it focused on obtaining a thorough analysis and awareness, as well as that which would contribute to further study. The specific focus upon evaluating the methodological design in terms of measures, approaches and samples used, was a result of the future projects which would be included in this thesis. The methodological design was split into various sub-categories for analysis. These included study sample, sample demographic information, sample size, methods enlisted, whether an intervention was used, and if so, and its duration.

#### **4.4.6 Stage 2: Identify relevant studies.**

Stage 2, identifying relevant studies, was viewed as important in balancing the breadth of the study, with the research question and purpose having a role in the decision making (Levac *et al.*, 2010). In alignment in Arksey and O'Malley (2005), search sequences were identified, as well as plans for searches of grey literature.

##### **4.4.6.1 Search procedure**

A thorough search of four databases was conducted. The databases searched were ERIC, PsychInfo, Springer, and ProQuest Social Science Collection. Appendix 1 displays the search sequences and number of results from each of the databases.

An academic librarian provided guidance when selecting these databases, as well as trialing search sequences with limits of results. Their expertise included selecting databases that included a range of journals relevant to the discipline and those which the institution had full access to. The date of publication was set in all four databases as being on or after the first of January 1999. The decision to limit the publication date was a result of the unmanageable number of results collected through a single search used as a pilot. Additionally, this date range still encompassed several editions of the primary diagnostic criteria used in autism assessments (APA, 2000; 2013). All searches were specified to only include peer reviewed sources and those published in the English Language. Once searches had been completed, all results were exported to EndNote in order collate findings from all databases. Within Endnote, searches were saved within a sub folder for the database that they had come from. Whilst the initial number of results was very high, through the removal of duplicates, this became more manageable. Only removing duplicates at the end of the searching process was considered the most efficient use of time.

In addition to the database searches, grey literature was sought through wider reading and access to articles the researcher already collected. This included searching journals' websites for recent publications (publications identified through search sequences), searches of key terms in Google Scholar (key terms extracted from search sequences), and the researcher's engagement with the online repository,



ResearchGate. ResearchGate was utilised as the researcher could receive alerts when articles were published that met criteria they defined. These criteria reflected the search sequences and key terms previously defined. Another strategy used was reviewing the reference lists of all the articles included after sifting, for any other articles to be reviewed for suitability for inclusion.

This approach to searching grey literature was beneficial, as including all synonyms for each term within the search sequences would have been unrealistic, as well as identifying articles where the lexis used was not identified through the researchers search sequences. An example of this is the terminology used to describe one's diagnosis, such as Aspie. Furthermore, allowing time to search for and include grey literature enabled relevant findings to be included if initially their titles or abstracts had not warranted inclusion through the systematic refinement process.

Whilst the scoping review method enabled the collection of many articles through standardised stages, there was still the possibility of bias. Specifically, during screening processes, decisions to include and exclude articles were made by a single researcher. As a result, they may have been influenced by personal interpretations and understandings. It would have been advantageous to include an additional researcher to limit possible bias, however this was not feasible within budget and time constraints. It would be preferable in future reviews to triangulate decisions made about the inclusion or exclusion in at least some of the articles. In addition to the possibility of bias within the screening stage, articles which had misleading titles or ones that did not reflect the content, may have prematurely been removed. As previously discussed, the search for, and inclusion of grey literature was a mediating effect of this possibility.

Search terms encompassed the key themes to be studied and ensured that the findings would be valid and address the aims and questions outlined in the early planning processes. Through the inclusion of common synonyms and colloquialisms, it was hoped that research which would be rich and meaningful would be included. The research questions identified were key considerations when designing the sequences, for example, the focus upon the social world influenced the areas and concepts included. The multi-disciplinary nature of the field of autism led to

terminology used in various fields to be included, for example, relationships, mental health, and technology.

Each search sequence was designed using the same structure, made up of three or four words that followed a structure widely used, with considerations of population, concept, and context (PCC). This formula was adapted to include terminology and concepts associated with this specific review, and included:

1. one variation of a term associated with autism.
2. at least one term to identify the target sample demographic, and
3. at least one term to identify the area or concept to be considered.

Table 7 demonstrates the different terminology utilised within the PCC.

<b>P</b>	Female, teenagers or young adults, diagnosis of autism
<b>C</b>	Friendships, relationships, communication, social engagement, social media, mental health, emotions, anxiety
<b>C</b>	Autism, additional needs, development, social navigation and management, social world

*Table 7: The PCC for inclusion in this scoping review.*

The search sequence below demonstrates how the structures above were enlisted within the design process: Autism Spectrum Disorders (1) “AND” Female\* (2) “AND” social world (3). These components were also considered within the inclusion criteria of articles throughout the data sifting process.

A total of 144 search terms and sequences were identified prior to beginning searches, with them being replicated across the databases. In the ProQuest and PsychInfo databases, search results were specified as being within the title, abstract, key words, but not in the full text (NOFT). Unfortunately, this option was not available in the other two databases, so an additional requirement of the first word in each sequence was decided. Without this, the number of results would have been vastly increased and not feasible within the study. As a result of the various databases formats, additional care was taken to ensure the findings were appropriate. To do this, a small-scale pilot of three search sequences in two

databases was conducted. This was hoped to limit the chance of problems arising during the larger data collection.

#### **4.4.6.2 Inclusion criteria**

Standardised inclusion criteria were identified prior to commencing searches, with exclusion resulting on an article not meeting these criteria.

These criteria were:

- The article had been published in the English Language.
- The article had been published between January 1<sup>st</sup> 1999 and the current day.
- The article was of peer review quality.
- Autism was a significant, or primary focus within the article.
- The article had been identified through the database searches or the search for any grey literature.

Databases were explored for functions that would reduce the time associated with refinement, for example, specifiers around the date of publication and language. Inclusion and exclusion criteria were chosen to ensure that the population to be studied and the field of study would be applicable and meet the research aims. The formulation of the sequences, as discussed above, served to identify articles that would meet the broad research aims. Further inclusion and exclusion were decided based upon each articles ability to answer the more specific research questions, utilising a pre-determined staged approach. Henceforth, described as data sifting.

#### **4.4.7 Stage 3: Study selection**

The contribution to Arksey and O'Malley's (2005) framework in the third stage, study selection, was focusing upon ensuring an iterative process was maintained, for example, when reviewing articles (Levac *et al.*, 2010). Furthermore, clear inclusion and exclusion criteria were established, primarily focused upon the date of publication, language of publication, and being of peer-review quality (Arksey & O'Malley, 2005).

#### **4.4.7.1 Data collection, storage, and sifting.**

Results for each database search were directly imported into reference manager EndNote to collate findings. In addition, the final group of publications to be reviewed were stored through EndNote within a separate folder. As searches were completed, the number of results were also noted on a Microsoft excel spreadsheet to keep a record of the totals (presented in appendix 2). This documented the results for each individual search within each database, as well as the number of articles being reviewed in each stage of sifting (represented in Prisma Diagram in section 4.5.2). This provided a visual representation of the stages of sifting and the exclusions at each one. The design of the review was outlined in a protocol prior to commencing data collection and included sections mirroring those in this section of the thesis.

The selection process was made up of several stages, based upon each articles ability to contribute to the review. The stages were:

- Stage 1: Following the collection of the literature, any replications were removed.
- Stage 2: The titles of the articles were screened, and any that were deemed not to be applicable removed.
- Stage 3: The abstracts of the remaining articles were screened, and any that were deemed not applicable were removed.
- Stage 4: The remaining articles were screened in full, and any that were deemed not to be applicable were removed.
- Stage 5: Any articles which were deemed not suitable to be included, or those which the researcher did not have access to, were removed.
- Stage 6: An additional stage like that of 5, but with a more specific focus upon meeting the three key areas identified within the inclusion criteria.

The need for a staged sifting process was influenced by previous reporting's of standardised search sequences eliciting unrelated studies (Arksey & O'Malley, 2005). This enabled the research to focus upon the research questions and eliminate those which did not meet or contribute towards that. Badger *et al.*, (2000) cited that abstracts were not always representative of the full text, which was a significant consideration

during the planning and protocol drafting. Arksey and O'Malley (2005) appear to support this by obtaining and evaluating the full texts of those deemed to fulfil inclusion criteria. It was beyond the scope of feasibility and time for this approach to be mirrored, however it helped to shape the six-stage process adopted in this review.

Upon comparison to another scoping review, the stages adopted in this review were considered to facilitate equally strong design and ability to identify articles meeting the inclusion criteria and those able to contribute to the research questions. Differences were identified in the review by Tint and Weiss (2016), namely that titles and abstracts were screened as a single stage, with the full text screening being a subsequent stage. Despite the varying descriptions of the data sifting stage of the review, all share the common goal of including articles which meet the inclusion criteria and contribute to the identified research questions.

#### **4.4.8 Stage 4: Charting the data**

Similarly, stage 4, charting the data, was reinforced as an iterative process where 'memoing' was used throughout the analysis of articles, as well as supporting the manual charting that was undertaken. However, Levac *et al's* (2010) suggestion surrounding the qualitative content analysis approach was not employed in this review.

##### **4.4.8.1 Data extraction and charting**

The evaluation of the included research papers took the form of two main types of analysis: numerical charting and qualitative thematic analysis. Such evaluation mirrors that identified more broadly as being an integral part of the scoping review method (The Joanna Briggs Institute, 2015). As a result of this two-part process, an iterative process was able to be maintained (Levac, Colquhoun & O'Brein, 2010; Arksey & O'Malley, 2005).

Once the data sifting was completed, remaining articles (n=26) were analysed to document the key characteristics and information about them. As suggested by The Joanna Briggs Institute (2015), the categories of information to be extracted was

defined during the protocol planning stage to ensure it was completed in the same way for every article. The areas which were extracted from each source were:

- Author(s)
- Funding notes / conflict of interests
- Year of publication
- Origin/country of origin (where the study was conducted and / or published)
- Aims/purpose.
- Study/population, sample size and demographic features
- Methodology and methods enlisted.
- Intervention type and details
- Duration of the intervention or measurement period
- Outcomes of measures
- Key findings that related to scoping review
- Identified limitations.
- Implications and areas for future research

Where there lacked information for a specific characteristic, the box was left blank. Excel was used to collate the extracted data, as well as the continued use of EndNote to store details and links to access the sources. In addition, once data was collected and themes generated, the extracted information was categorised to aid analysis. Where common themes were identified, there were added to, rather than replacing the primary data extracted.

#### **4.4.9 Stage 5: Collate, Summarise and reporting of the results.**

The final stage, collating, summarizing, and reporting the results, incorporated Arksey and O'Malley's (2005) guidance of identification of key themes and key domains, as well as utilising Braun and Clarke's (2005) thematic analysis framework. The categorisation of steps in this stage were in three tiers, one, analysing the data, two, reporting results, and three, applying meaning to results (Levac *et al.*, 2010).

#### **4.4.9.1 Charting**

When the information was extracted from all included articles, each area was independently examined to collect statistical representations of the data. In other, more qualitative areas, such as limitations, findings were categorised, and a tally of frequency across all articles noted. These were not decided prior to the commencement of the project, as it was an adaptation of the process resulting from the unexpected number of qualitative comments obtained during charting. Some data extracted for specific areas was directly quoted, as this reduced the chance of misinterpretation or bias. In some areas of summary, articles were able to be attributed to various themes or topics. For example, in summarising the limitations identified in each of the articles, their descriptions could be tallied to numerous topic areas. Typically, these areas of comparison were that representing qualitatively based data. In comparison, areas of quantitative data, such as date of publication, were only tallied to one measure.

#### **4.4.9.2 Thematic analysis**

Paper-based thematic analysis followed the six-stage design identified by Braun and Clarke (2006), which focused upon familiarisation with the texts, developing initial ideas, to links across articles, to overriding themes. It was enlisted as part of the review due to its credits as being a foundational method of qualitative analysis, as well as not being attributed to any specific theoretical framework (Braun & Clarke, 2006). More recent discussions highlight the role of reflexivity in thematic analysis, addressing the researcher's subjectivity as an analytic resource, with a role in the engagement with theory, data and interpretation (Braun & Clarke, 2021). Furthermore, in a reflection to their 2006 publication, Braun and Clarke (2021) highlighted that they did not fully acknowledge the diversity of thematic analysis and the need for researchers to specify their orientation to thematic analysis. Therefore, conceptualisations of thematic analysis acknowledge different versions (Braun *et al.*, 2021a).

The main process of thematic analysis involved six stages of manual coding and note making, and then drawing together key, overriding themes through the latter stages. During the middle stages where themes were in their infancy, they were considered in

relation to the review aims, as well as how they would contribute to our knowledge. The initial description of the conceptualisation of themes stage has been reflected upon to address the confusion identified (Braun & Clarke, 2021b). Themes in reflexive thematic analysis have been subsequently defined as patterns of shared meaning that are united by an idea or concept (Braun & Clarke, 2013; Braun *et al.*, 2014). The six stages are described and summarised below:

### **1. Stage one: familiarisation with data**

This stage of analysis was focused upon immersion with the articles included in the review. This focuses on establishing the context for each of the articles, their format, and the meaning behind the findings. This stage was completed prior to codes being defined. As a result of the amount of reading to be completed, memoing throughout the active reading of each article was undertaken. This was considered to map out and record the thoughts and possible codes and helped identify sections of articles which were of specific interest for more detailed analysis.

### **2. Stage two: generating initial codes.**

Through the generation of initial codes, data and themes were organised into meaningful groups (Tuckett, 2005). Each article was evaluated for codes and notes made, with the themes and categories being compiled. Specific care was given to ensuring the context of each individual article and memo was not lost within this process (Bryman, 2001).

### **3. Stage three: searching for themes.**

This stage was re-focusing analysis on broader themes that had emerged from the data set, rather than focusing upon individual codes, and a consideration of any relationships between themes. This stage again benefited from creative measures to map out the codes, themes, and ideas about links. For example, previously written post-it notes were moved around on a mind map and tables of the theme and coloured pens were used at different stages to enable the developmental trajectory of ideas to be followed. The themes identified during this stage were categorised to identify those which were most significant, and those which were less clear. This helped in focusing attention, whilst not losing sight of the themes which may need more clarity.



#### **4. Stage four: review themes**

Themes identified in the mind-mapping process were written and presented in order of prevalence and significance so they could be reviewed against all 26 articles. Each theme was considered in turn, with any articles which it featured being listed against it. This enabled themes to be considered in the entirety of the data set rather than within a single article. This stage also included consideration of whether some of the identified areas were significant to constitute as a theme or would be better defined as a subtheme of another title. At this stage, these decisions were preliminary. Themes which were considered to lack clarity in stage 3 were analysed, and a decision was made whether they were to be included under another theme (or subtheme), or they were not significant enough across the data set as whole. Possible themes were written on blue post it notes, and sub themes on yellow. This enabled them to be moved easily to ensure that themes were separate, made sense, and did not encompass too many broad subthemes.

#### **5. Stage five: define themes.**

This stage focused on ensuring decisions about themes and subthemes were representative of the dataset. In addition, time was taken to ensure that the nature of each theme was clear, for example, if the theme title was representative of all subthemes. Establishing that all themes contributed to or linked with the research questions was an important consideration throughout analysis, however, it was given increased focus in this stage. Finally, once refinement of themes and subthemes had been completed, a thematic map representing the themes and their relationships was created.

#### **6. Stage six: Writing up**

The writing up of this review forms a thesis chapter that provides evidence of the conclusions made, in enough detail that it could be replicated in future. The writing up of the themes gives an overview and specific examples of the themes in citations to individual sources.

Whilst there was expected to be a large amount of rich data gained through analysis, the reporting mainly focused on the themes which had emerged and providing a few

examples from the articles. Quotations from articles are included where they are considered to demonstrate and support the argument being discussed. In addition, thematic analysis has also considered any implicit meaning or ideas which were identified during analysis. Reporting of the findings takes the form of written analysis, as well as a visual figure to present the themes and subthemes identified.

#### **4.4.10 Ethical approval and considerations**

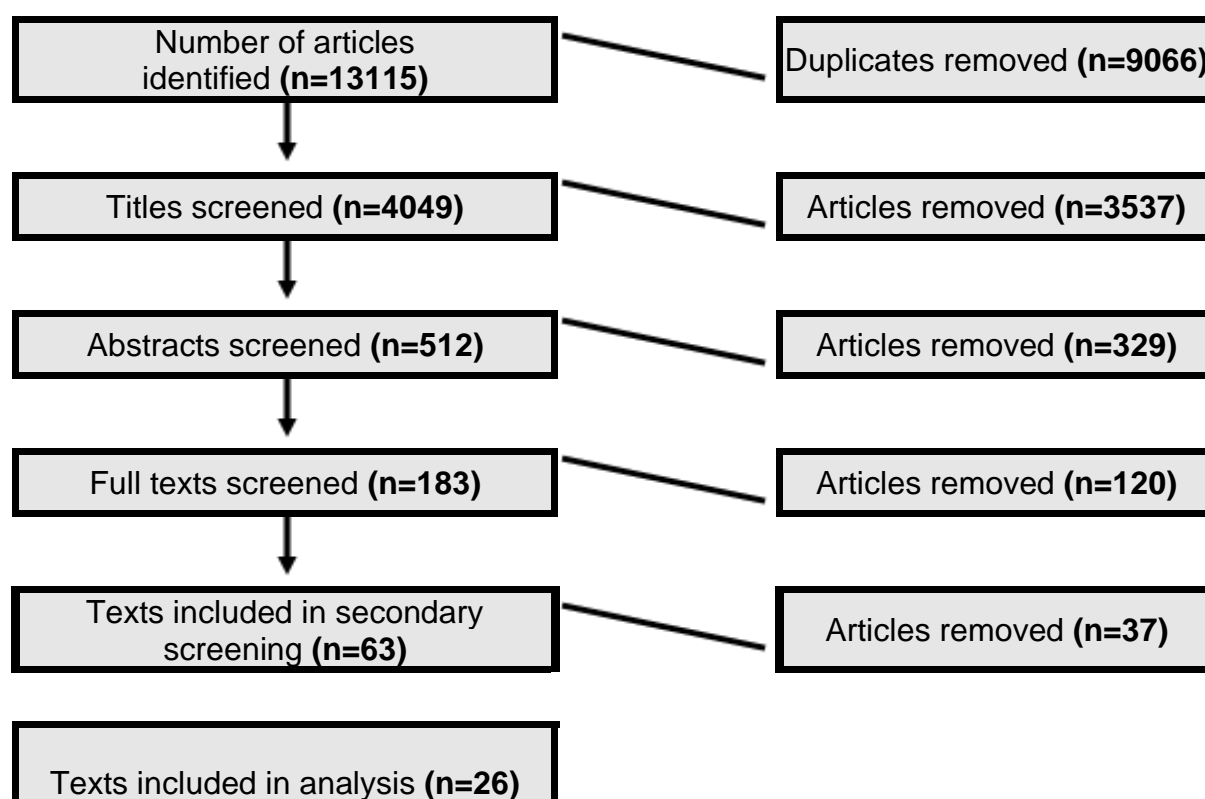
As this project used secondary data analysis, and therefore not actively including research participants, ethical considerations were minimal. As the research papers had already been published online, and accessed through university subscription, this again lessened ethical considerations. This considered, to ensure that the work was known to be being undertaken, it was recorded on the university's online ethics page whereby predicted start and end dates were recorded, as well as a brief description of the study. To support this, a research protocol was written to outline the need for the review to be undertaken, as well as identifying the method which would be used to collect the data and how it would be analysed. This protocol was discussed and reviewed with both research supervisors, as well as considered in line with the wider research aims attributed to the PhD.

### **4.5 Results**

#### **4.5.1 Scoping Review findings - summary**

A total of 26 articles were included in this review. These articles were published between 2002 and 2019, with sample size ranging from 0 (highlighted in a review paper) to over 500. These articles were reviewed through charting and thematic analysis (Braun & Clarke, 2006). Charting highlighted the inclusion of topics such as friendships, loneliness and social challenges, and a range of qualitative, quantitative, and mixed-method designs. The thematic analysis highlighted seven themes, each with linked subthemes. These included the theme of the social world, coping strategies and the effect of gender. Sub-themes (n=21) included models of disability, social validation, and camouflaging.

#### 4.5.2 Description of the evidence base - charting



*Figure 3: PRISMA diagram of the collected results and refinement of articles in the review.*

From the four databases used, there were a total of 13115 articles identified, within this, the majority were collected from ProQuest Social Science collection and Psych Info (5632 and 5333 respectively). Once duplicate findings had been removed from the results, 4049 results had their titles screened to evaluate their appropriateness to the study. This stage of refinement resulted in 3537 results being removed, leaving 512 for further evaluation. The reasons for excluding an article were not documented, though some reasons that appeared include there being a medical focus or approach and a population dissimilar to the target. Further evaluation of the abstracts from the results again significantly reduced the number of results to 183. At this stage, reasons for exclusion included a quantitative design and the prevalence on second or third hand accounts. Articles that had a primary purpose of evaluating a measurement tool were removed. Upon assessing the full texts, an additional 114 articles were removed, and 6 further were excluded during due to the lack of availability of the full text.

Following these stages, the the total number of articles (n=63) was considered to provide an unrealistic amount of data to be analysed. As a result, an additional stage of refinement was included to remove articles that were weaker in their ability to meet the aims of the review. Specifically, this included considering: the life stage focused upon (adolescence), the overall topic (well-being, life experiences, presentations) and links to the social world. Each of these three areas were applied to each article, resulting in an additional 37 articles being removed. Therefore, a total of 26 articles were included in the review.

#### 4.5.2.1 Summary of each article (n=26)

Paper number	Author(s)	Year	Country	Empirical study	Quantitative	Qualitative	Friendship	Camouflage	Anxiety/MH	Sample gender*	Finding' s summary
1	Ahlers <i>et al</i>	2017	USA						✓	NA	In a review of literature, three challenges of social development commonly experienced by individuals with ASD were explored (anxiety, social isolation, grief). Also, they identified evidence-based practices, learning strategies and lists of practical resources.
2	Ashbaugh, Koegel & Koegel	2017	USA	✓		✓				OH F	This study included 3 participants selected from a group based on the severity of their level of social engagement with peers. Structured social planning was the method of intervention – for example, organizational skills, peer mentors and social skills training. All three participants increased social integration, including the number of community based social activities, extracurricular activities and peer interactions.

3	Ashburner, Ziviani & Rodger	2010	Australia	✓	✓					MM	A case-control research design was used to compare teaching ratings in areas such as academic performance for 28 students with ASD and 51 age and gender matched typically developing students from the same mainstream classrooms. Two questionnaires were used. Individuals with ASD are likely to have higher levels of behavioural and emotional difficulties. No themes or findings were discussed specifically considering gender.
4	Barendse et al	2018	Netherlands	✓	✓	✓	✓			MM	This study compared the mentalizing skills and emotional recognition abilities of 'high-functioning' adolescents with ASD and 21 matched controls. Data was gathered from parents and young people using different tools. Parental reports suggest those with ASD have less friends and spend less time with friends. Individuals do not always agree. In some areas, ASD and TD have little/no differences.
5	Bauminger	2002		✓	✓	✓				MM	This study evaluated a 7-month cognitive behavioural intervention of 15 'high-functioning' children with autism'. Assessment was carried out through observations and pre-defined measures. Intervention made improvement of all areas of RRB's. Individuals more able to recognize emotional cues. Increase in positive interactions.

6	Bauminger, Shulman & Agam	2003	Israel	✓	✓	✓				MM	This study examined understandings and feelings of loneliness in 18 'high-functioning children with autism' and 17 typically developing children. Observations were undertaken in addition to a range of assessment methods, for example, the loneliness rating scale. TD higher peer interaction, HFA more socially active, quality same. HFA higher than ASD. Loneliness understanding equal in ASD and HFA, but more reported in ASD.
7	Bauminger <i>et al</i>	2008	USA	✓	✓	✓				MM	This study evaluated 26 mixed friendships (autistic child and friend with typical development) and 16 non-mixed friendships (autistic child and friend with disability) using methods such as interviews, questionnaires from participants, their friends, and parents. Mixed dyads more stable and higher positive social orientation. In mixed groups, autistic children had less leadership opportunities than non-mixed.
8	Bermudez <i>et al</i>	2015	Spain	✓	✓				✓	MM	This study included 38 children and one parent for each. Using a self-report tool (SCARED), children and parents completed the 41-item tool. Parent-child agreement was found to be limited, with all areas showing anxiety perceived by parents to be higher than children. Significance was found in total anxiety, generalized anxiety factor and social phobia, with all others non-significant.

9	Biggs Carter	&	2016	USA	✓	✓					MM	This study examined subjective health and wellbeing of 389 transition-age youth with autism or intellectual disability using the parent proxy version of the KIDSCREEN-27. Parental ratings of quality of life were significantly lower than similar age youth (consistent with research on younger children) – the lowest area was social support and peers. Some difference was identified between category – with autistic youth having a greater difference. Positive factors for wellbeing, such as community involvement and religion were identified.
10	Bostrom Broberg	&	2018	Sweden	✓	✓	✓				OH M	This mixed-method study engaged with 10 students who completed the WellSEQ and took part in a semi-structured interview. The aim was to explore experience of well-being, mental ill-health, for example, in students in special education. Overall, there was agreement between the two measures, though the questionnaire did not appear to capture all aspects of significance. Most students expressed mainly positive mental health. Participants were able to communicate their experiences. Emphasis on family and school as positive and restrictive.

1 1	Bottema-Beutel <i>et al</i>	2016	USA	✓		✓				MM	In this study, 33 autistic youth (age 14-24) were interviewed about seven areas related to interventions, involving scoring components and providing an explanation. Autistic adolescents have diverse preferences in preferences for intervention design and delivery. Chi-Square tests indicated most prevalent high ratings within recruiting peers and family involvement. Qualitative themes included effect of disclosing disability and advantages of learning through shared activities. Recruiting peers with similar interests/who engaged in similar was preferred over existing peer groups or teachers selecting peers. Meeting without an adult was preferred to adult presence. Shared activities were preferred over direct instruction as a context for learning social skills.
1 2	Cage & Troxell-Whitman	2019	UK	✓	✓			✓	✓	OH M	In this study, 262 autistic people (135 females, 111 males, 12 other) completed measures of camouflaging behaviours, contexts, reasons, and mental health symptoms through the CAT-Q, rating statements from 'strongly disagree, 1' to 'strongly agree, 7'. There are various reasons for and benefits of camouflaging, influenced by gender and age of diagnosis. Low camouflage = lower stress/anxiety. Reasons for camouflaging were highlighted in two categories, conventional (to get by in formal setting, e.g., work) and relational (to get by in relationships with other).



1 3	Callus	2017		✓		✓	✓			MF	This study utilized a focus group of seven members of a self-advocacy group (all categorized as someone with intellectual disability) to explore how they experience friendship and what it means for them. Demographics of participants were varied in areas such as age, gender, and living arrangements. Varied understandings of friendship; spending time with someone, having respect, with reciprocity being the most common theme identified Complexities of, and different types of friendships. Behaviours and actions that foster friendship and those that undermine it were identified.
1 4	Chamberlain, Kasari & Rotheram-Fuller	2007	USA	✓	✓					MM	<p>This study included 398 participants in regular classes, including 17 with a confirmed autistic diagnosis. Data was collected through peer reports and self-report on topics such as loneliness and peer acceptance. Whilst autistic participants were involved in social networks, they experienced lower centrality, acceptance, companionship and reciprocity, however no greater loneliness.</p> <p>There were similar levels of security and conflict with differences between own and others' views of self.</p>

1 5	Chen <i>et al</i>	2014	Australia	✓	✓					E	<p>This study had a sample of 4 autistic individuals aged 16-31. Using an electronic device, they were prompted to complete a survey 7 times a day, at random times over 7 days. It aimed to evaluate the feasibility and usefulness of the app to capture everyday experiences of autistic people. Participants were found to be able to reflect in the moment on thoughts, experiences, and emotions. No significant correlation was found between ratings of 'degree of involvement' and 'enjoyment'.</p> <p>.</p>
1 6	Chen <i>et al</i>	2015	Australia	✓	✓		✓			OH M	<p>This study included 14 Australian and 16 Taiwanese autistic individuals. Using the tool cited in article 15 (Chen <i>et al.</i>, 2014), participants carried a device to prompt them 7 times a day for a period of 7 days to complete records of information, for example, what they were doing, reasons for engaging in the situation and the perceived difficulty. Cognitively able more motivated to interact with others. Social activities/interactions support psychological needs and motivation. Limited time was spent in social situations, though participants did demonstrate motivation. Overall, the study highlighted how in-the-moment information about individuals' experiences may facilitate better support to be created.</p>

17	Chen <i>et al</i>	2017	Australia	✓	✓				✓	OH M	This study utilized the same participants as study 16, though the focus was on cross-cultural differences in the two samples. Australian participants and females were more likely to spend time in situations which require social interaction than Taiwanese and males, respectively. In addition, people who had fewer ASD symptoms and those with higher levels of social anxiety were less inclined to engage in social interaction. Cultural expectations also may contribute to the finding that females with ASD, regardless of nationality, engaged in more social activities. Findings were consistent with previous research.
18	Clark, Magill-Evans & Koning	2015	USA	✓	✓					MM	This study included 3 girls and 19 boys with ASD and a parent for each. A range of self and proxy reporting tools were used to explore perceived quality of life. Autistic participants report lower average. Lowest scores in social support/peers category. There were some differences between self and parental report, parents give lower scores typically. Average self-report scores were within one standard deviation of the mean compared with typical developing samples.

19	Cook, Ogden & Winstone	2018	UK	✓		✓	✓	✓		AF	This study conducted semi-structured interviews with autistic girls and one of their parents from mainstream and specialist settings. It sought to explore how autistic girls experience learning, friendships and bullying. Findings indicated a difference in perception of friendship, with many having trouble maintaining friendships, though, there remained a desire for these. Masking behaviours were highlighted, specifically the potential for problems to result from it and subsequent internalization of problems (greater stress and anxiety). Thematic analysis identified themes and codes, of which, parents only identified some (e.g., absenteeism, social isolation, problem of late/missed diagnosis), but none were singularly identified by the children.
20	Cridland <i>et al</i>	2014	UK	✓		✓	✓		✓	AF	This study used semi-structured interviews to explore experiences of autistic teenage girls. 3 girls and their mothers were interviewed, along with an additional 2 mothers. The main themes included diagnostic challenges, impact of 'being surrounded' by boys, high school experiences and the complexity of relationships. The issue of maintaining friendships with NTD peers was considered unique to females.

2 1	Hebron & Humphrey	2014	UK	✓	✓	✓			✓	MM	This study utilized data from a larger data set focusing on education provision for CYP with SEND. Teachers (N = 722) and parents (N = 119) of children and young people with ASC drawn from 269 schools across 10 Local Authorities (LAs) in England participated in the Study. Factors were identified that may predict increases (risk) or decreases (protection) in exposure to bullying for autistic CYP. Factors included mode of travel to an educational setting, educational placement and behaviour difficulties.
2 2	Jamison & Schuttler	2015	USA	✓	✓						Using a quantitative design, this study used data collection materials to compare autistic females to typically developing peers. Significant differences were found in groups in self-rating of social-emotional health and problematic behaviours. Non autistic peers rated themselves higher across all areas. Parental reports indicated a positive correlation between symptom severity and negative impact on social competence. Autistic females perceived themselves to have lower social competence, self-worth and quality of life.

2 3	Milner <i>et al</i>	2019	UK	✓		✓	✓	✓		AF	This study used a qualitative methodology to explore the female experience of autism. 18 autistic females and 4 mothers took part in discussions focused on diagnosis, impact and coping. Using thematic analysis, five themes were identified (fitting the norm, obstacles, negative aspects, perspective of others, positive aspects of autism). Various strategies to mask reported along with negative consequences. Difficulties with friendships were mentioned, but still girls still desired them.
2 4	Sedgewick <i>et al</i>	2016	UK	✓	✓	✓	✓			OH F	This mixed-method study examined gender differences in social motivation and friendship experiences in boys and girls with and without autism (sample size 46 total). Autistic girls showed similar social motivation and friendship quality to non-autistic girls, whilst boys reported different to non-autistic boys and non-autistic girls. Teachers report female with less difficulties. Key area of focus being conflict. Females' friendship centre on people not activities or objects, greater social motivation.
2 5	Tierney, Burns & Kilbey	2016	UK	✓		✓	✓	✓		AF	This study interviewed 10 autistic adolescent females to explore their experiences of managing social relationships. Themes included; feeling unable to fit in, Increasing challenges in adolescence, some development of secondary diagnoses, . negative impact of coping strategies and barriers to making/sustaining friends.

26	Vine Foggo & Webster	2017	Australia	✓		✓	✓			AF	Seven participants were included in this study who all took part in a semi-structured interview to explore social interactions and friendships. Findings identified interactions are important, but that they are difficult. These difficulties appear more in bigger groups, with conflict an area of stress. Participants often over apologetic and have a desire for approval/reassurance. Time to de-stress and engage with their preferred interests was an important protective factor.
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*Table 8: A summary of the included articles.*

\*Sample gender codes

NA	Not applicable
NS	Not stated
AF	All female
MF	Majority female
OHF	Just over half female
E	Even
OHM	Just over half male
MM	Majority male
AM	All male

*Table 9: Acronyms used in table eight and meanings.*

Data was extracted from all articles for sixteen standardised areas, including of numerical and explicitly cited information, rather than interpretations and analyses of articles (see appendix 3 for sample of data extraction). Some topics, such as key findings, warranted a more detailed summary to be extracted. These were formed similarly to that of paraphrasing. A summary of the key findings from the charting process are outlined and discussed below.

26 articles were subject to charting and thematic analysis as part of this review. These articles were written in a variety of countries internationally, though as expected, the largest proportions were from the USA (n=8) and the UK (n=7). The publication dates ranged from 2002 up until 2019, with a spread across these years. An interesting finding was that from 2014 and 2018 inclusive, over 80.77% of articles were published in these years. Diagnostic criteria have been exposed to various revised editions over the time covered in this review (DSM IV-R, APA, 2000; DSM V, APA, 2013). As a result, these changes were considered alongside the publication dates of studies included in this review. Whilst the reasoning for the inflation of articles from 2014 are not concrete, it is likely that the diagnostic developments have some effects. The extent of this increase cannot be identified yet, though a similar review to this in five to ten years may be able to retrospectively explore this further. This finding of a recent increase is consistent with McPartlan and Volkmar (2013).

When evaluating sample sizes in the articles, categories with upper and lower limits were decided, for example, between one and five participants. There was no category which was significantly greater than any other, with six out of the seven categories obtaining at least 3 articles. A similar method of categorisation was enlisted when considering the gender demographics of participants in the included studies. Categories were identified prior to the data collection, and focused upon whether there was a single gender, or a mixed demographic, which was further separated into the proportion of one in relation to the other. For example, two categories were majority male, just over half male. As expected, the most met category was that of majority male samples (n=11). Interestingly, whilst no article included an all-male sample, 5 articles included a fully female sample, which included relatively low sample sizes. Whilst the reasoning for this is unknown, it is postulated that this is a result of an increasing awareness and consideration of the individual experiences of autistic females. The findings surrounding the gender of participants included in the articles were not surprising, as the prevalence of males in samples has been reported on several occasions (Baron-Cohen *et al.*, 2011; Fulton *et al.*, 2017; Lai *et al.*, 2013; Sipes *et al.*, 2011). Despite this finding, the inclusion of female participants, and in a small number of articles the larger proportion of females, is representative of the growing body of research with regards to gender.



On analysis it was found that those with higher numbers of females, presented aims more directed towards gaining an understanding of a specific concept, as opposed to testing a pre-defined hypothesis of the relationship between two variables. Furthermore, these findings were drawn from the conclusions made by studies including a larger portion of males. Specifically, these findings contained various reference to being able to meet specific levels and skills. The consideration of ability appeared to take prevalence over considerations of emotional and mental health. As a result of the highly male samples, the implications of the findings should be viewed with caution when applying to females. This caution is supported by articles who did include females.

Methodological design was considered in this review's analysis as well as all articles. They were categorised into either: review of literature, qualitative, mixed method, quantitative and intervention. Quantitative measurement tools and a mixed method approach were the most frequently prevalent category (n=8 and n=9 respectively). The large proportion enlisting a quantitative methodology correlated to the high number of standardised tests cited in the measures enlisted. Articles that utilised a mixed-method (n=9) or qualitative approach (n=6) predominantly relied on semi-structured interviews as a data collection tool, often focusing upon the measurement of difficulty, rather than the perceptions of the difficulty. A surprising theme which emerged through the charting process was that in mixed method studies personal experiences were compared with proxy reports resulting in rich data being collected. The use of standardised measurement tools brings statistical significance to finding and they also represent a medicalised model of disability. Stipulations of average IQ in many empirical studies provided interesting evaluation. Misconceptions and stereotypes of autism often include considerations of ability, and through the management of IQ in samples, this challenges this.

Specifically, limitations surrounding the sample demographics of empirical studies were cited in 17 articles. As a result, charting took place to establish various demographic features of the samples. 24 articles included samples with a diagnosis of ASD, HFA, Autistic disorder, and Asperger's Syndrome. The sample of the remaining study was defined by the broader term of Intellectual Disability (ID). 6

articles (23.08%) included a comparison between groups of typically developing peers, with 1 study comparing to a sample with Dyslexia. The reporting of comorbid diagnoses in some samples of autistic groups was cited in 5 articles (19.23%), some specifically providing the additional diagnosis, for example, anxiety and depression. Considerations of autism alongside comorbid diagnoses bring to light the complexity of difficulties experienced by participants. The awareness of this complexity brings forward the multi-disciplinary nature of autism. Whilst there was a great deal of variability identified through charting, there was an overriding awareness that differences in presentation and management strategies are likely to be because of gender.

There were various limitations identified within the discussion of each article, which included sample demographic and sample size. Limitations identified in several studies (n=12) included those associated with using a specific standardised measurement tool, as well as the overall methodological approach. The analysis of identified limitations facilitated a consideration of whether such limitations were representative of all autism and disability research, or an individual study. Each article was considered individually, and a tally was kept of the limitations cited, meaning they could be counted within several, or just one limitation category. It was somewhat expected that limitations surrounding the sample would be the most highly cited, however, an interesting addition to this focused upon all but one of the other limitations fitting under the umbrella term of 'methodological limitations'. The area that did not fit under this term was that of there being limitations in the background literature available prior to the study being undertaken. Whilst this limitation was only explicitly cited on one occasion, within several articles the background and discussion sections did include some evaluation of literature, along with considerations of where gaps are and how they may be filled.

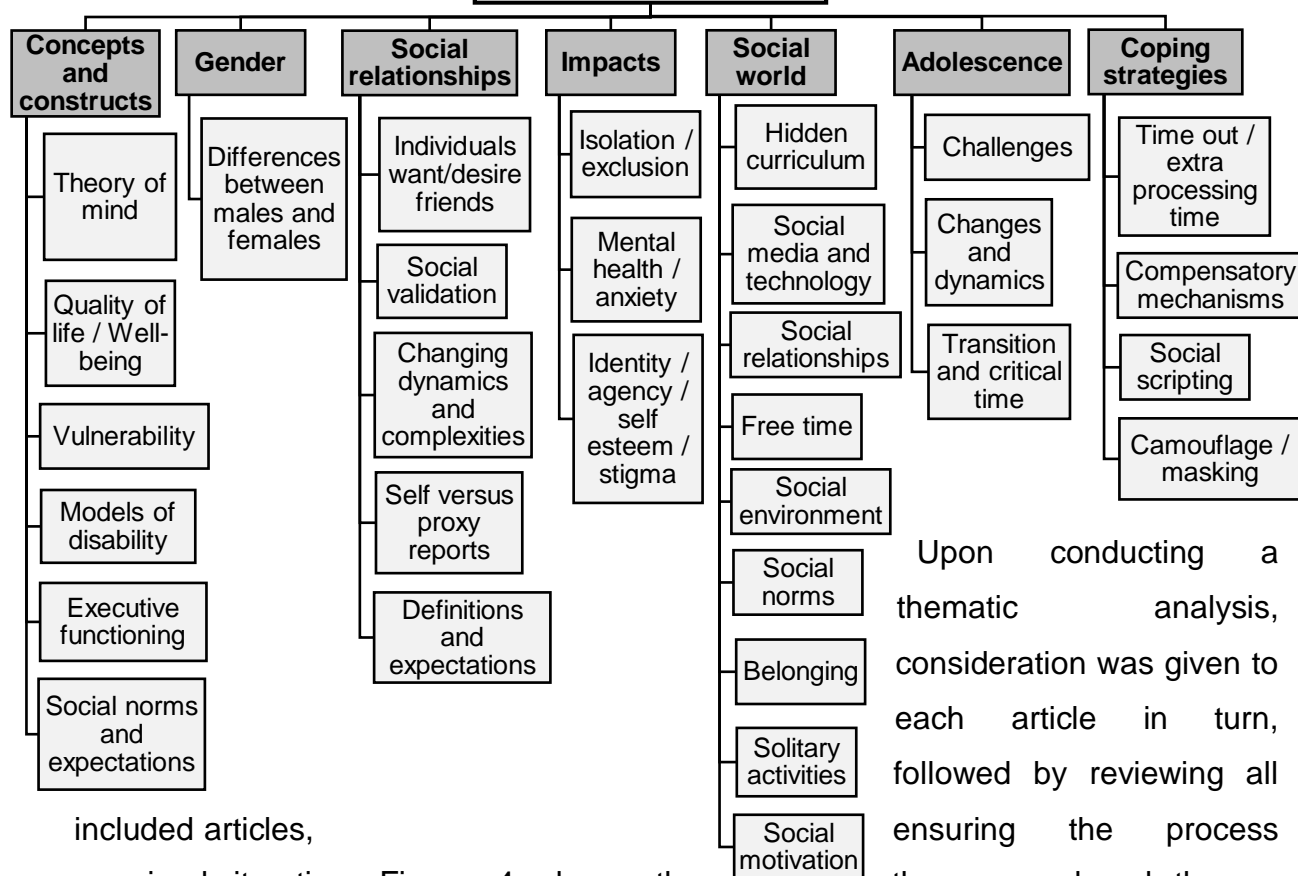
Findings from the review provided guidance as to possible topics considered within the domain of the social world. Through categorising the themes of findings, the social considerations were evident. Specifically, friendship, peer interaction, social challenges and school challenges were found, mirroring findings by Chevallier *et al.*, (2012). The influence of technology and social media was not present at the levels predicted, this may be a result of the date of included articles. In addition, the specific

influence of technology and social media is a more recent development, and as such, may not have featured in research more broadly. Though, as Abel, Machin and Brownlow supported it as an importance in research in a 2010 publication, it may be concluded to demonstrate a gap in literature.

A final note which emerged through the charting process was that the aim of articles often focused upon testing a hypothesis, rather than investigating a phenomenon in a specific population.

### 4.5.3 Description of the evidence base – thematic analysis

#### 4.5.3.1 The process of **Thematic analysis themes** identifying themes.



included articles, remained iterative. Figure 4 shows the themes and sub-themes that were identified.

Upon conducting a thematic analysis, consideration was given to each article in turn, followed by reviewing all ensuring the process themes and sub-themes

*Figure 4: Initial themes and subthemes identified through analysis.*

Succeeding that, they are discussed along with quotes from included articles. A table that outlines which themes and sub-themes were identified in each article can be found in appendix 4.

The same researcher collected, refined, and analysed the articles included in this review, thus demonstrating the familiarisation with the data. Active involvement in the refinement process enabled the researcher to get a pre-existing familiarity with the articles prior to analysis commencing. An in-depth account of the researchers position within the topic area is presented in chapter one. Through the staged approach of thematic analysis, more detailed understanding and evaluation of each article was undertaken, allowing for themes to be defined and categorised. The familiarity with the data set was beneficial when drawing comparisons and validating themes towards the later end of the analytic stages where the number of subthemes was perceived as needing further refinement. This refinement also drew upon the knowledge of the topic area to present the themes in a more logical way and categorised more appropriately. Whilst the thematic analysis included clearly defined stages, the researcher's memos, and thoughts upon first reading each article were utilised to guide the subsequent codes ascribed to the data.

Notes were made when conducting the analysis in addition to a regular contribution to a field diary and mind mapping of themes and topics as they emerged throughout the process. As the researcher has experience of the topic area, analysis utilised this to conceptualise the themes. In addition, this enabled the researcher to conduct the refinement processes to reflect the topic area and the articles that contribute to the research aims. In the initial thematic analysis, seven themes and thirty-one subthemes were identified. These were subsequently refined to reflect the prevalence of the individual themes to ensure a balanced view was presented. Following refinement, the

Initial theme and subtheme		Refined theme and subtheme
Concepts and constructs: theory of mind Concepts and constructs: executive functioning	→	Concepts and constructs: theory of mind/executive functioning
Concepts and constructs: social norms and expectations Social world: social norms	→	Social relationships: social norms and expectations
Social relationships: individuals desire/want friends Social world: social relationships Social world: social motivation	→	Social relationships: desire and motivation for friends
Social relationships: definitions and expectations	→	Social relationships: definitions of friendship
Impacts: mental health/anxiety Concepts and constructs: quality of life / well-being	→	Impacts: quality of life/well-being/mental health
Impacts: identity, agency, stigma, self esteem Social world: belonging	→	Impacts: identity/agency/self-esteem/stigma/belonging
Social world: free time Social world: solitary activities	→	Social world: solitary activities/free time
Social relationships: changing dynamics and complexities Adolescence: changes and dynamics Adolescence: transition and critical time	→	Adolescence: transition period/changes in dynamics/critical time
Coping strategies: time out/extra processing time Coping strategies: compensatory mechanisms	→	Coping strategies: time out/extra processing time

same seven themes were included, though the number of subthemes was reduced to twenty-one. Figure 5 demonstrates the changes made:

*Figure 5: Sub-theme changes from first analysis to final refinement.*

Overall, the final themes and theme titles were developed iteratively throughout the analysis, involving the complex processes described above, drawing upon the expertise of the researcher.

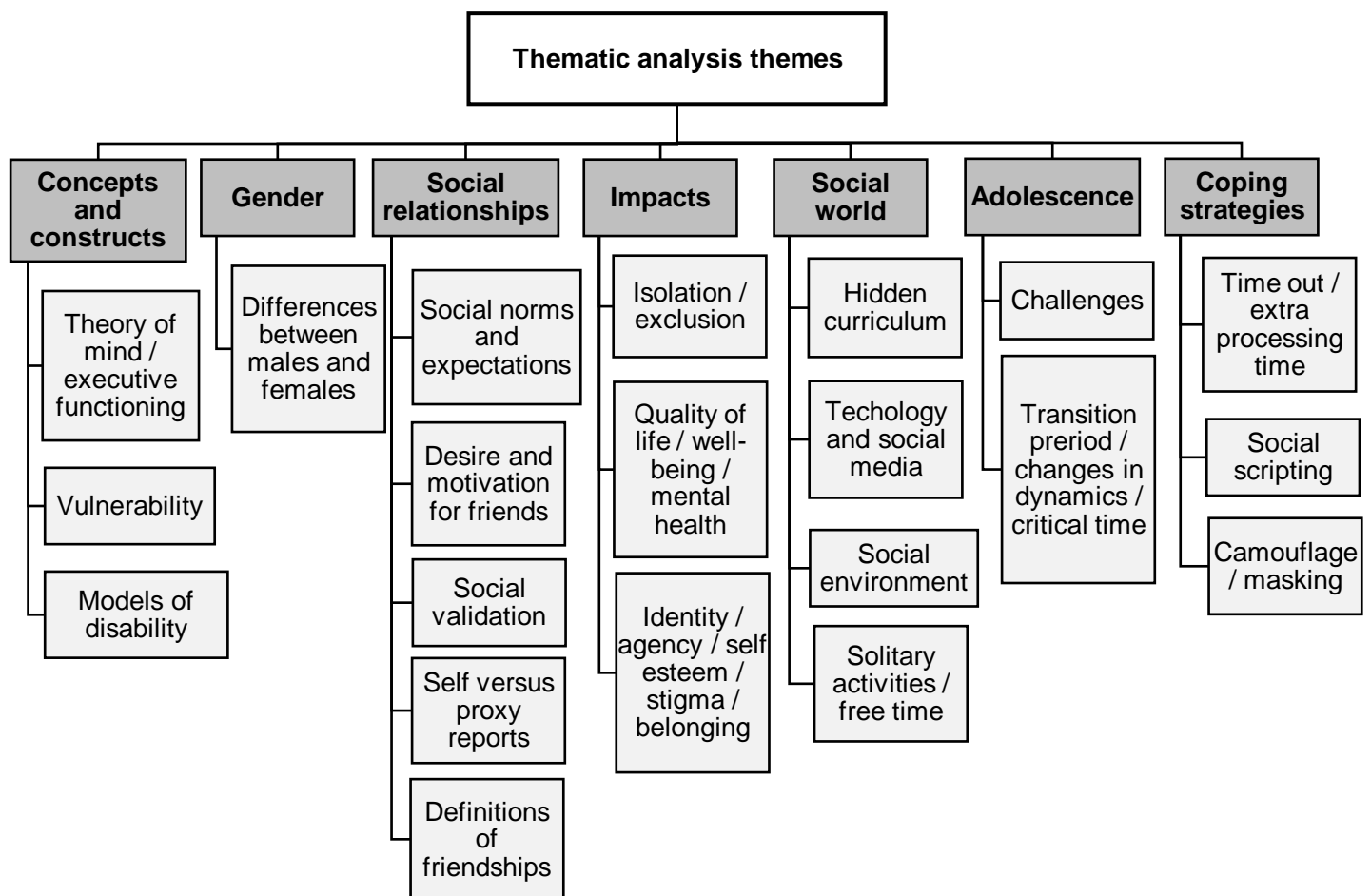


Figure 6: Revised themes and subthemes identified through thematic analysis.

#### 4.5.3.2 Theme 1: Concepts and constructs

Upon analysis of all included articles, three concepts and constructs were cited, with a varying prevalence overall. Within this theme, several subthemes also emerged: Theory of Mind, Executive functioning, models of disability and vulnerability. The theme of models of disability encompassed both medical and social models of disability, which were reflected in the measurement tools and frameworks used. The authors' positioning is likely to be influential, as well as the nature of the topics explored. Some articles were more explicit in the model of disability shaping discussion. For example, article 8 (Bermudez, Sanchez, del Sol & Sevilla, 2015) enlisted several quantitative questionnaires to measure various aspects of anxiety, as well as citing the importance of *'treatment'*. This is seen to represent a medically based model of disability. In contrast, Article 13 (Callus, 2017) specifically cited using *'the social model*

*of disability as the conceptual framework'*, with this being identified in the qualitative nature of data collection. Another interesting consideration comes from article 19 (Cook, Ogden & Winstone, 2018), which actively discusses both biological and social models, and the influences they have on social relationships.

Following on from considerations of models of disability, an additional sub theme identified was that of the perceived vulnerability of those with an autism diagnosis, whether that be in research, or day to day life. Article 3 (Ashburner, Ziviani & Rodger, 2010) considered how the vulnerability of autistic individuals may increase negative experiences, such as bullying and isolation. Further, negative experiences described in this article are:

*"likely to be exacerbated in secondary school where they (autistic student) must contend with multiple classes and teachers... and the social pressures of adolescence..."* (Ashburner, Ziviani & Rodger, 2010, p. 26).

In addition, article 20 (Cridland, Jones, Caputi & Magee, 2014) considered the increased vulnerability of autistic individuals to exploitation, specifically in females. Another example where vulnerability was considered was within article 22 (Jamison & Schuttler, 2015), describing vulnerability in relation to receiving a diagnosis of a comorbid mental health difficulty. In addition, the increased complexities in social interaction during adolescence were discussed as a contributing factor to these diagnoses.

*"these findings support the postulate that adolescent females with ASD are more vulnerable than their typically developing counterparts due to the compounded impact of ASD symptoms on social-emotional health and the higher risk for internalizing disorders for adolescent girls"* (Jamison & Schuttler, 2015, p. 53).

Whilst authors provided research support for understandings of vulnerability, there was limited exploration of how these perceived negatives could be improved. Furthermore, many of the reports of vulnerability were identified in proxy reports, and therefore may not fully demonstrate the complexity of the concept in this population.

Theory of mind and executive functioning are cited and implied through many articles. For example, article 4 (Barendse *et al.*, 2018) discusses them in relation to positive and successful social interactions and relationships. In addition, Barendse *et al.*, (2018) discuss how:

*“although mentalizing problems in individuals with ASD have been a major topic in autism research since the early 1980s, there is still little information available on the mentalizing abilities in high-functioning adolescents with ASD...”*  
(Barendse *et al.*, 2018, p. 546).

These were further considered in article 7 (Bauminger *et al.*, 2008), specifically in the reciprocity of friendships, and the possibility for difficulties experienced by autistic individuals.

#### **4.5.3.3 Theme 2: Gender**

This theme was expected due to the criteria used when constructing search sequences, as well as inclusion and exclusion criteria. The focus of this theme is the presented discussions of differences between males and females, as well as an awareness that gender should be considered a variable in the field of autism. The nature and significance of this did vary between articles, however the consideration that it is an area which needs further exploration was mirrored throughout most articles.

Article 9 (Biggs & Carter, 2016), in its discussions of quality of life, identifies gender and other demographic factors, for example cognitive functioning, as factors which may contribute to the presentation and difficulties experienced for autistic individuals. Article 12 (Cage & Troxell-Whitman, 2019) considered gender in the specific area of camouflaging, and elicited findings that gender had a significant effect in camouflaging for ‘*conventional reasons*’, but not ‘*relational reasons*’. This article also cites how:

*“autistic women’s experiences can be considered within an intersectional framework – whereby autistic women are marginalised due to the male-focus that has dominated discourse about autism...early definitions of autism were borne out of observations of males and diagnostic instruments have mostly*



*been developed based on male responses...*" (Cage & Troxell-Whitman, 2019, p. 1900).

In a fully female sample, article 19 (Cook, Ogden & Winstone, 2018) explores camouflaging in relation to social relationships. Conclusions focus upon the perceptions and experiences of friendships having the potential to differ for females, as well as the need for professionals to have an awareness of both academic and social needs. Further, when acknowledging the high male-female ratio of autism, differences in an individuals' presentation were proposed as an important factor:

*"...boys are more likely to receive an earlier diagnosis since they show greater signs of aggression, whereas girls with autism, particularly those with advanced verbal skills...appear to be coping well. The perceived ability of girls to cope is problematic...it can cause the internalization of their problems...many are not being diagnosed"* (Cook, Ogden & Winestone, 2018, p. 312).

Through data obtained by parental proxy reports, article 20 (Cridland *et al.*, 2014) discusses the common perception that autistic females have a higher desire for acceptance by their peers, in comparison to autistic males. Furthermore, it goes on to suggest the need for *'female specific groups'* to support the *'unique issues they face'* (Article 20; Cridland *et al.*, 2014, p.1272). Support for the idea of female specific issues can be seen in article 22 (Jamison & Schuttler, 2015), which presents comparisons in several domains between individuals with and without autism, focusing upon gender. A specific finding of note was that of higher internalising symptoms, lower ratings of self-worth, quality of life, and social competence in females with and without autism. In addition, all three areas of study (social competence, self-worth, quality of life) resulted in significantly lower ratings in autistic females than peers without autism.

A final consideration within this theme was the differences of sociability in males and females. This was discussed specifically within article 24 (Sedgewick *et al.*, 2016), and whilst the cause was expressed as being *'unclear'*, societal gender roles and social sensitivity were considered as being important in how *'social disabilities are manifested in girls on the autism spectrum'* (Article 22: Jamison & Schuttler, 2015, p.1304). Article 17 (Chen *et al.*, 2017) considers the influence of societal gender roles, describing how:

*“The higher levels of sociability in females may be, in part, the result of social expectations, where women are expected to display more frequent social and communication behaviours than males...”* (Chen *et al.*, 2017, p. 232).

#### **4.5.3.4 Theme 3: Social relationships**

The third theme surrounding social relationships consisted of six subthemes, which include social norms and expectations, the desire and motivation for friendships, social validation, changes in dynamics in friendships, self-versus proxy reports and definitions of friendship. Autistic individuals were considered to want and desire social relationships, specifically friendships. This was widely discussed in all but one article (Ahlers *et al.*, 2017; Ashbaugh, Koegel & Koegel, 2017; Barendse *et al.*, 2018; Bauminger, 2002; Bauminger, Shulman & Agam, 2003; Bauminger *et al.*, 2008; Bermudez *et al.*, 2015; Biggs & Carter, 2016; Bostrom & Broberg, 2018; Bottema-Beutel *et al.*, 2016; Cage & Troxell-Whitman, 2019; Callus, 2017; Chaimberlain, Kasari & Rotherham-Fuller, 2007; Chen *et al.*, 2014, 2014, 2017; Clarke, Magill-Evans & Koning, 2015; Cook, Ogden & Winstone, 2018; Cridland *et al.*, 2014; Hebron & Humphrey, 2014; Jamison & Schuttler, 2015; Milner *et al.*, 2019; Sedgewick *et al.*, 2016; Tierney, Burns & Kilbey, 2016; Vine Voggo & Webster, 2017), though some key themes can be drawn.

Article 1 (Ahlers *et al.*, 2017), a review of previous literature, discuss that whilst individuals with autism are not as successful in social engagement, there is still the desire to seek and have friendships. Discussions also include how ‘*many individuals with ASD are capable of forming reciprocal friendships...*’ (Ahlers *et al.*, 2017, p. 590). A level of intrinsic motivation for social and solitary activities was identified in the sample in article 16 (Chen *et al.*, 2015), with the desire for social relationships being cited to be ‘*context specific*’. The conclusion drawn from the data produced by participants in this article was that:

*“cognitively able adolescents and adults with ASD were motivated to interact in situations where they felt competent and experienced social reciprocity...they were motivated to engage in social activities where they did not experience significant difficulty...”* (Chen *et al.*, 2015, p. 2706).

Similarly, article 19 (Cook, Ogden & Winstone, 2018) describes the firsthand reports of the desire for friendships and to fit in, though there were also reports of these interactions being unsuccessful. In addition, cultural expectations are considered to contribute to findings that “...*females with ASD...engaged in more social activities...*” than males (Chen *et al.*, 2017, p. 238). However, article 21 (Hebron & Humphrey, 2014) describe how participants voiced “*a clear sense of feeling different from other people...*” (p. 29). Participants understanding of friendship, and subsequent discussion in article 10 (Bostrom & Broberg, 2018) highlighted the importance of “*having something to do and being around others rather than closely interacting...*” (p. 172). This was considered to highlight the need to reconsider the definition and conceptualisation of friendships for autistic young people and those with other additional needs (Bostrom & Broberg, 2018). On the other hand, Cook, Ogden and Winstone (2018) drew comparisons between autistic and non-autistic samples, citing how ‘*autistic girls’ motivation for friendship is nevertheless similar to their non-autistic peers*’ (p. 303).

Drawing upon theoretical views of “*the core deficits in ASD*”, difficulties in the domain of friendships has been described as:

*“due to the difficulties in understanding other people’s thoughts, desires, and feelings (i.e., theory of mind deficits) and / or due to lack of the basic ability to experience relationship-based emotions, leading to difficulties in developing affective closeness and intimacy...”* (Bauminger *et al.*, 2008, p. 1212).

Social norms and expectations were discussed in several articles, specifically in how these may present difficulties for autistic individuals, as well as their possible influence upon the identification of difficulties. Article 5 (Bauminger, 2002) articulates how ‘*cultural norms, conventions, and rules of behaviour*’ can complicate understandings of emotions for autistic people. Considerations of social expectations are further explored in article 12 (Cage & Troxwell-Whitman, 2019), specifically in how there are socially constructed views of what autism ‘*looks like*’. When considering the effect of gender on social relationships, article 14 (Chamberlain, Kasari & Rotheram-Fuller, 2007) identifies the presence of ‘*gender-related interests, such as video games...*’, as well as article 17 (Chen *et al.*, 2017) discussing the perceived better social ability in autistic females to be a result of social expectations.

Concepts of validation and reciprocity for autistic individuals was identified as central within friendships (Article 13; Callus, 2007). An overall awareness among articles discussing this subtheme (Ashbaugh, Koegel & Koegel, 2017; Callus, 2017; Chamberlain, Kasari & Rotherham-Fuller, 2007; Cook, Ogden & Winstone, 2018; Jamison & Schuttler, 2015; Tierney, Burns & Kilbey, 2016) was that the desire to have friends was often enhanced by the desire to fit in and fulfil social expectations. Social validation was often reported as being achieved through negating and avoiding negative social experiences, for example rejection. Through adolescent participants, article 25 (Tierney, Burns & Kilbey, 2016) reports participants' strong desire to '*not stand out*', with a successful interaction or relationship providing social validation. Further, findings outline how:

*"...participants conveyed desire for friendships, their motivations for making friends and some of the challenges to making and/or maintaining friends. All participants described having a desire to have friends. This intrinsic motivation combined with experience of frequent peer rejection, sometimes stirred up ambivalent feelings about friendships; participants wanted friends but had to go to great lengths to make and maintain friendships..."* (Tierney, Burns & Kilbey, 2016, p.77).

Article 2 (Ashbaugh *et al.*, 2017) utilises an intervention to "*assess whether a structured social planning intervention would increase social integration for college students with ASD...*" (p.183). The inclusion of this article within this subtheme is a result of it being perceived as a proactive response to understanding that this group are more likely to experience challenges within social validation during this transitional period.

Within the theme of social relationships, the review highlighted the awareness that the dynamics, complexities, and expectations were changing and becoming more intense in adolescence, specifically for females. This was discussed in many articles, both through explicit focus within the aims, and secondary focus through studies' findings (Barendse *et al.*, 2018; Bauminger *et al.*, 2008; Callus, 2017; Chamberlain, Kasari & Rotherham-Fuller, 2007; Cridland *et al.*, 2014; Hebron & Humphrey, 2014; Jamison &

Schuttler, 2015; Sedgewick *et al.*, 2016; Tierney, Burns & Kilbey, 2016; Vine Foggo & Webster, 2017). Article 7 (Bauminger *et al.*, 2008) considers friendship in two sample groups: single dyad of autistic individuals, and mixed dyad with autistic and typically developing peers. Findings suggest significant differences in the characteristics of friendships in these two groups. Article 13 (Callus, 2017) similarly focuses upon experiences of friendship in autistic individuals, with a significant weight placed on reciprocity by participants. The citing and importance placed upon reciprocity is a theme which is prevalent within this subtheme and the wider theme of social relationships. Article 20 (Cridland *et al.*, 2014) describes the increasing complexity of social relationships during adolescence, with increased challenges for autistic individuals due to the reliance on intimate relationships. The changes experienced for individuals with an autism diagnosis were cited as being a result of the social norms associated with the period of adolescence, as well as expectations of females (Article 22; Jamison & Schuttler, 2015). Article 25 (Tierney, Burns & Kilbey, 2016) goes on to explicitly describe how:

*“females with ASC face a different set of social expectations and norms to males with ASC” (p.81).*

Perceptions of friendships were measured in several ways through the articles included in the review, from self-reports, to reports by parents and peers. Interestingly, differences were found in reports of individuals and primary caregivers (specifically parents). Article 18 (Clark, Magill-Evans & Koning, 2015) include specific measurement tools in several areas to explore the differences between reports. A specific finding of note was that parental scoring of social support and peers was lower than individuals' perception, and overall, there was a significant theme of parental scoring being lower than that provided by the individual. Specific reports and measures of anxiety in article 8 (Bermudez *et al.*, 2015) demonstrate a limited parent-child agreement. Namely, anxiety levels in all factors were perceived higher by parents than those manifested by children. Whilst including both parental and self-accounts from females about educational difficulties during adolescence, article 20 (Cridland *et al.*, 2014) include conflicting areas identified as negative:

*‘Negative aspects of high school raised by girls with ASD included finding the class work difficult and/or uninteresting, challenges making friends, and managing the larger school environment... Negative aspects raised by mothers*

*involved mainstream teachers' limited knowledge of ASD symptomology in girls...* (Cridland *et al.*, 2014, p.1266).

In addition to discussions of friendship, article 18 (Clark *et al.*, 2015) discuss quality of life and the role of various reporting tools to gain the most accurate understanding. Specifically, this was discussed in the role of self-determination and proxy-reporting:

*"...proxy-reporting should not replace self-determined QoL ratings at least for those individuals capable of providing information...it may be helpful to include multiple proxy respondents..."* (Clark *et al.*, 2015, p. 62).

The definitions and expectations of social relationships is subject to change during adolescence. The centrality of peer interactions is described in article 11 (Bottema-Beutel *et al.*, 2016) as being the primary focus within one's social life. In addition, these definitions and preferences in relationships were identified as influencing the success of social interventions (article 11; Bottema-Beutel *et al.*, 2016). Article 13 (Callus, 2017) places a specific focus upon friendship and described the variation that individuals can place on the desire for and importance of friends, though, the sample was not singularly focusing upon autism. A feature among the various themes discussed around friendship, was that:

*"they are all based on the concept of reciprocity...given that most people with intellectual disability live lives which are heavily circumscribed by others and therefore experience relationships which are unequal..."* (Callus, 2017, p.10).

Whilst not focused on adolescence, the differing perceptions of friendships among autistic and typically developing individuals featured in article 14's exploration of children's social networks in regular classrooms (Chamberlain *et al.*, 2007). The finding of relevance within review stems from the difference between:

*"...how children with autism see themselves, and how others see them, socially in the classroom. In general, children with autism see themselves as more socially involved than their peers report...and they are less sought out for 'hanging out' together..."* (p. 239).

The concept of acceptance featured throughout considerations of social relationships, specifically through citing of a high level of importance placed upon this in article 20 (Cridland *et al.*, 2014). Overall, an awareness of the variability of definitions and understanding of friendships was identified through this review. In addition, the effect of this, and the challenges which this may pose for autistic adolescents, has not been a primary aim or consideration. Article 26 (Vine Foggo & Webster, 2017) is close in its focus upon autistic females' friendships during adolescence, as it considers more broadly '*social experiences*' (p. 74), with the predominant topic being friendships. Conclusions from this study include the acknowledgement that there is a '*stereotypical notion that adolescent females on the spectrum don't understand friendship*' (p. 83). The conclusion provided in this article presents a synthesis of the subthemes identified in this review as well as drawing links with topics in other themes:

*"not only did the participants in this study show a desire for and enjoy close friendships...their understanding with what they considered to be difficulties associated with social situations were met with constructive solutions. For example, rather than isolate themselves... when faced with social challenges, the participants recognized their own need to incorporate individual down time..."* (Vine Foggo & Webster, 2017, p. 83).

#### **4.5.3.5 Theme 4: Impacts**

A frequently highlighted area amongst the body of research collected for this review was that there were possible impacts on autistic individuals when considering experiences of the social world. Specifically, these were categories around 3 sub-themes:

- Quality of life / well-being / mental health
- Isolation / exclusion
- Identity / agency / self-esteem / stigma / belonging.

Isolation in autistic individuals was considered in article 1 (Ahlers *et al.*, 2017), a review of literature. Specifically, it concluded that autistic people experience '*anxiety and social isolation on a regular basis*'. A possible consequence of isolation and exclusion is that of loneliness. Within this article, commentary focused upon interventions for such isolation and exclusion:

*“There are two basic approaches...the first is a skill-building approach to increase appropriate social interactions and motivations through direct instruction, social stories, and scripting...the other approach is to increase the capacity of peers to include students with ASD... (Ahlers, et al., p. 596).*

Article 6 (Bauminger, Shulman & Agam, 2003) support this with higher feelings of emotional and social loneliness being reported in autistic individual's compared to typically developing children. In addition, the location and context of social interaction were considered influencing variable, as *“children with autism presented more social isolation in less structured social environments (e.g., free play vs. lunchtime)”* (Bauminger, Shulman & Agam, 2003, p. 490).

Perceptions of inclusion within social groups was a focus within article 14 (Chamberlain, Kasari & Rotherham-Fuller, 2007), with findings suggested that autistic individuals reported their inclusion and roles more highly than their peers. This presents interesting findings surrounding how autistic individuals and typically developing peers consider inclusion and its importance, as well as possible explanations for the differences in reports. Specific contexts where exclusion may occur were reported as being those outside of the educational environment, for example birthday parties (Article 19; Cook, Ogden & Winstone, 2018).

Within article 21 (Hebron & Humphrey, 2014), participants' understanding of their diagnosis was discussed, including descriptions of *“the utility of the diagnostic label”* being clear (p. 29).

Quality of life was reflected through most articles, mainly through consideration of negative or undesirable consequences or concurrent difficulties associated with having a diagnosis. Article 9 (Biggs & Carter, 2016) discussed the quality of life of autistic individuals, with a specific focus on the limited knowledge of how disability affects quality of life during the transition to adolescence. Further, through parental reports of children with autism or an intellectual disability, quality of life scores was:

*“significantly lower than a normative sample of similar-age youth...the domain with the lowest ratings...was social support and peers...”* (Biggs & Carter, 2016, p. 200).



Article 18 (Clark, Magill-Evans & Koning, 2015) can be considered the most influential article regarding its consideration of quality of life, as its primary aim was to consider this from both individuals and parents. It also cited the importance of including adolescent reports to '*ensure that their perceptions are heard*' (p.63). The prevalence of considerations of quality of life is demonstrated using measurement tools being designed to measure self, and proxy perceptions, for example, the youth quality of life instrument (Article 26; Vine Voggo & Webster, 2017).

Mental health was considered in several articles (Ahlers *et al.*, 2017; Bermudez *et al.*, 2015; Cage & Troxell-Whitman, 2019; Chen *et al.*, 2015; Clark, Magill-Evans & Koning, 2015; Cook, Ogden & Winstone, 2018; Cridland *et al.*, 2014; Hebron & Humphrey, 2014; Jamison & Schuttler, 2015; Milner *et al.*, 2019; Tierney, Burns & Kilbey, 2016), through explicit citing's of comorbid diagnosis, as well as reporting of various anxiety and stress scales. For example, article 25 (Tierney, Burns & Kilbey, 2016) discusses how core difficulties in autism result in the development of a secondary mental health condition. Higher rates of internalising symptoms are considered higher in autistic females. This, in addition to the complex social relationships during adolescence, is described as a '*double hit*' for adolescent females (Article 22; Jamison & Schuttler, 2015). Article 21 (Hebron & Humphrey, 2014) enlisted a tri-group comparison of mental health profiles in adolescents. Of which, the group with autistic adolescents experienced significantly greater anxiety, depression, anger, and lower self-concept than those without additional needs, as well as significantly worse than those with another diagnosis (Dyslexia). Drawing upon the discussions of anxiety, article 8 (Bermudez *et al.*, 2015) utilises self and parental reports of anxiety to generate a comparison across the 41-items of the SCARED instrument. Findings indicated that:

*"... parent-child agreement is limited. In all the factors, the anxiety levels perceived by the parents in their children are higher than those manifested by the children. These differences were significant in the total score of anxiety, the generalized anxiety factor, and the factor of social phobia..."* (p. 2534).

The consideration of mental health featured in many articles, but overall, concern was focused on the possibility for this to overshadow difficulties associated with autism or be explained by a diagnosis of autism and thus ignored. This subtheme links closely

with the theme of adolescence, specifically in it being a period where mental health difficulties are increasingly reported.

The importance for participants in article 25 (Tierney, Burns & Kierney, 2016) to appear to fit in and comply with social norms was discussed, and descriptions of masking or camouflaging were considered alongside perceptions of identity. Considerations of personality characteristics and perceptions of oneself to others was categorised under the subtheme of identity, and were identified in many articles (Barendse *et al.*, 2018; Bauminger, 2002; Bauminger, Shulman & Agam, 2003; Bottema-Beutel *et al.*, 2016; Cage & Troxell-Whitman, 2019; Callus, 2017; Chamberlain, Kasari & Rotherham-Fuller, 2007; Clark, Magill-Evans & Koning, 2015; Cook, Ogden & Winstone, 2018, Cridland *et al.*, 2014; Hebron & Humphrey, 2014; Jamison & Schuttler, 2015; Milner *et al.*, 2019; Tierney, Burns & Kilbey, 2016).

Linking to social experiences and loneliness, simply having higher levels of social involvement does not negate the risk of negative consequences, as autistic children may experience:

*“...rejection from peers because of their peculiar social functioning (e.g., lack of reciprocity), and thus these youngsters may reveal less social involvement than expected on the basis of their social abilities...”* (Bauminger, Shulman & Agam, 2003, p. 490).

The disclosure of autism amongst peers was perceived to present several challenges. For example, in article 11 (Bottema-Beutel *et al.*, 2016) both positive benefits of acceptance, and negatives of stigma were reported. In negative views, disclosure is positioned as *“a potential source of ridicule”* (Bottema-Beutel *et al.*, 2016, p. 203), whereas more positive views consider disclosure to be:

*“an opportunity to instill ‘interactional expertise’ in their neurotypical peers, which can bridge the empathy gap created by insufficient knowledge about the autistic experience...”* (p. 203)

Linking to reasons for masking or camouflaging difficulties, participants in article 12 (Cage & Troxell-Whitman, 2019) reported negative reactions when disclosing their diagnosis, as well as shame surrounding their identity. This was also described as

their ‘autistic identity’, which did not always fit into the identity that they wanted to portray within social circles. A final consideration of identity was discussed in article 22 (Jamison & Schuttler, 2015), specifically alongside social complexities for female adolescence. This was described as an intersection, with a sense of self being highly influenced by success, or difficulties in social domains.

#### **4.5.3.6 Theme 5: Social world**

The term ‘social world’ is one which includes several sub-themes. One or more of these were identified within 16 articles. The sub-themes were:

- concepts of a hidden, or unscripted curriculum associated with adolescence.
- experiences of solitary activities and free time
- the social environment.
- social media and technology.

The idea of a hidden curriculum was not explicitly cited within all the identified articles; however, it can be understood through various subthemes which present times when there are social norms expected but not taught. Article 21 (Hebron & Humphrey, 2014) describes how autistic individuals are aware of their difficulties in unstructured periods, for example breaks in the school day. In addition, this article explicitly cited the hidden curriculum when discussing the studies’ implications:

*“...the current study provides insight into the aspects of their social world that pose a particular challenge for girls on the spectrum. Gaining an understanding of these difficulties, and more importantly of the aspects of social relationships in which the girls are more comfortable, will aid parents and professionals in developing more specific and meaningful strategies to assist adolescent girls on the autism spectrum to negotiate the hidden curriculum of social relationships as they move from childhood into adolescence...”* (Hebron & Humphrey, 2014, p.82).

Social media and technological developments serve various purposes and can be linked to various challenges for autistic people. The reason for using technology was also considered, with engaging in conversation with peers was most frequent in female adolescent samples.

Social relationships were discussed, and specifically within the social world of an adolescents were complex (article 20; Cridland *et al.*, 2014). The processing of social information was considered a challenge faced by autistic adolescents, with close links to the desire to follow social norms (article 19; Cook, Ogden & Winstone, 2018). Experiences of the social environment were the most prominent influence on evaluations. For example, in article 25 (Tierney, Burns & Kilbey, 2016), it was considered a superordinate theme, describing feelings of '*distress, lack of safety and rejection*'. Positive experiences of friendship were reported in article 13 (Callus, 2007) when activities took place outside of the pre-determined environment and in an accessible way.

Social norms were identified and reported by many participants as an area requiring high concentration. For example, article 25 (Tierney, Burns & Kilbey, 2016) discuss how behaviours which unintentionally broke social convention would result in negative responses, and thus internalised feelings for individuals. Another area of social norms was cited in article 23 (Milner *et al.* 2019), surrounding concepts of gender and the expectations of behaviours and interests' one should have being a female and adolescent. This article also identifies '*fitting in with the norm*' as a theme through the qualitative analysis of data obtained. Article 22 (Jamison & Schuttler, 2015) specifically cites difficulty arising due to the changes in social norms experienced during adolescence.

Activities or time spent alone were reported to serve a variety of functions for autistic people. Whilst they are considered during the diagnostic process for autism, article 23 (Milner *et al.*, 2019) presents how they are often used as a coping strategy to manage the level of stimulation experienced during compulsory social times:

*"... 'I try to spend as much time alone as I can cos it really does like it gets me in a very calm state of mind so that when I do need to interact with people, I'm willing to talk and socialise" (FF05)'..."* (Milner *et al.*, 2019, p.2393).

This links to the choices of activity during free time. Article 17 (Chen *et al.*, 2017) describes most of the time was spent at home, with this mainly being alone or engaging in productive activities (for example, class work and household chores).

Similar findings were reported in article 16 (Chen *et al.*, 2015). Article 14 (Chen *et al.*, 2014) do however balance this with findings that *“participants enjoyed social activities and interacting with friends, even though they spent little time doing these things...”* (p. 365).

Various motivations to engage socially and experience social networks has been reported in many articles. The motivation reported by females in article 23 (Milner *et al.*, 2019) included that of engaging with peers and making friends. A specific finding arising from the synthesis of findings in article 26 (Vine Foggo & Webster, 2017) focused upon views of social interaction being important, with them also been considered an area of difficulty. In addition, article 24 (Sedgewick *et al.*, 2016) report differences in the social motivations of adolescent males and females, though this is positioned as unsurprising *“given that it is well known that neurotypical girls and boys have distinct friendship experiences...these differences may be a result of different socialisation patterns”* (p.1298). The importance of this in autism research is acknowledged as important because:

*“...knowledge of any differences in the social relationships of autistic boys and girls is (therefore)crucial for understanding potential pheno- typic differences and, if necessary, for developing more refined diagnostic tools and tailored interventions...”* (Sedgewick *et al.*, 2016, 1298).

#### **4.5.3.7 Theme 6: Adolescence**

Two sub-themes were identified under adolescence. The first, the challenges associated with adolescence, and the second, adolescence as a transition period with changing dynamics, and its role as a critical time in one’s life. Challenges within social relationships are considered exacerbated in adolescence as *“students encounter a more complex social landscape, and the role of adults changes...”* (Bottema-Beutel *et al.*, 2016, p. 196). In addition, article 20 (Cridland *et al.*, 2014) provides an in-depth consideration of adolescence and the specific experiences of autistic females through a synthesis of literature, concluding that:

*“...the literature in this area highlights that adolescence is a critical period for girls with ASD...”* (p. 1262).

The increasing desire for independence during adolescence has been discussed as challenging for autistic individuals, specifically when experiencing the ‘peer culture’ which often has stigma attached to adult involvement and support (article 11; Bottema-Beutel *et al.*, 2016). The challenges and negative experiences of social interaction during adolescence are linked to the increasing complexity of social expectations (article 20; Cridland *et al.*, 2014). The complexity of female friendships was also reported in this article to increase during adolescence. Changes in the motivation for social relationships, and the value placed on such relationships was cited in article 24 (Sedgewick *et al.*, 2016), with this bringing increased challenges for autistic females. Barriers which autistic people may experience during adolescence were cited and reported amongst numerous articles (Biggs & Carter, 2016; Bostrom & Broberg, 2018; Clark, Magill-Evans & Koning, 2015; Cook, Ogden & Winstone, 2018; Cridland *et al.*, 2014). For example, barriers to participation in community activities were reported in article 9 (Biggs & Carter, 2016).

The concept of adolescence being a period of transition was significantly inherent within article 9 (Biggs & Carter, 2016), with results supporting it being a critical period of development. The need for further research was cited, specifically in *“the strengths of young people with disabilities during the transition period”* (Biggs & Carter, 2016, p. 201) as positive characteristics can be associated with increased Quality of Life. Article 10 (Bostrom & Broberg, 2018) discuss the period of adolescence in relation to the role of their family relationships in the conflicting level of needs and expectations of independence:

*“...students in the present study described the family as mostly present and supportive. The dependent relationship experiences by students led to both a sense of satisfactions when they sometimes were allowed to manage independently but also to a sense of frustration when parents did not support their interests or wishes...”* (Bostrom & Broberg, 2018, p. 174).

#### **4.5.3.8 Theme 7: Coping strategies**

Whilst article 19 (Cook, Ogden & Winstone, 2018) acknowledge that *“to date, little is known about the experiences of girls with autism, or how they live with and manage their autism”*, this review has identified that three topics presented under the theme of

coping strategies. These include the role of time out and processing time, the use of social scripting, and the camouflaging or masking.

Consequences of navigating the social world are often considered to be negative, for example, mental health difficulties. Though, various strategies have been cited and described as managing negative outcomes, as well as facilitating participation and inclusion. This theme is primarily focused on camouflaging or masking of difficulties, but it also includes considerations of specific strategies used, for example taking time out of socially stimulating situations (e.g., article 1; Ahlers *et al.*, 2017). This was further discussed by Chen *et al.*, (2017), describing the social anxiety autistic individuals experience and the need for “*more time in solitude as self-initiated compensatory strategies...*” (p. 238).

An example provided by Chaimberlain *et al.*, (2007) provide a narrative directed from a parent about how their daughter “*...played completely by herself, in the proximity of other children who ignored her presence...*” (p. 237). Whilst this was not explored further, it is postulated that social scripting and a knowledge of the routines during the school day had an influence on this observation.

Camouflaging is a concept or a definition that featured significantly amongst the articles included in this review. It has been conceptualised and defined as enlisting strategies to hide, or mitigate difficulties experienced because of an autism diagnosis (Hull *et al.*, 2018). Whilst some explicitly investigated or discussed camouflaging or masking in their samples (article 12; Cage & Troxell-Whitman, 2019), others considered it when discussing the possible reasons for the results obtained (article 23; Milner *et al.*, 2019, article 25; Tierney, Burns & Kilbey, 2016). The extent to which this can be seen to show the full extent of this compensatory mechanism is questioned by sample limitations, as well as the measures used. Specifically, there is a limited number which are sample lead and enlist ethnographic or qualitative based approaches (in addition to the interview). Despite this, the aims identified in many included studies focused upon gaining more information as well as increasing positive experiences. Enlisting compensatory mechanisms, whatever the reasoning, has been cited as a possible explanation for the higher levels of social ability and functioning when using standardised measures (article 4; Barendse *et al.*, 2018).

Discussions within this article include questions of how compensation *“takes place”*, if it comes *“at a cost”*, and how it *“is modulated by the environment”*. (Barendse *et al.*, 2018, p. 553).

Article 19 (Cook, Ogden & Winstone, 2018) extends this to suggest the product of imitating successful the social interactions of peers is a strategy employed to mask difficulties. A reliance on this skill developed in early childhood was considered to facilitate social relationships, however, its success was considered to reduce during adolescence (article 20; Cridland *et al.*, 2014). An additional area in which camouflaging was reported was within measures of well-being, such as anxiety (article 21; Hebron & Humphrey, 2014). Specifically, concealing difficulties indicating coping, when this was not the case, increased the risk of negative consequences. Thus, it may be counterproductive.

Social-emotional understanding and social interaction in *“high-functioning children with autism”* (Bauminger, 2002, p. 283) was the focus of an intervention discussed in article 5. Whilst the outcomes of this do not explicitly cite the use of social scripting, the underlying concept of the findings aligns with social scripting and the ability to learn the appropriate responses and reactions in social interactions:

*“a qualitative change was evident in their examples of emotions; after treatment, these children demonstrated improvement in their ability to provide more specific examples of complex emotions...these findings, highlighting that emotions can be taught, and that social understanding can be improved...”* (p. 293-294).

Furthermore, when considering the role of compensatory mechanisms, these findings support the notion of cognitive compensation for *“social-emotional deficits in this population”* (p. 294).

Overall, various strategies that were reported focus upon limiting perceptions or demonstrations of difficulty. Strategies were mainly focused upon areas of social interaction, relationships, and communication, which mirrors key areas of difficulties for autistic individuals. The use of strategies to manage perceived difficulties has however costs and benefits, with participants mainly focusing on the benefits.



#### 4.5.4 Additional considerations

Where studies used standardised methods and measurement tools, these often focused upon a specific attitude or ability. Through the charting in this phase, a theme started to emerge that standardised methods correlated to the aim of increasing positive experiences and outcomes for autistic people, as opposed to the aim of developing understandings of social navigation strategies autistic teenage girls use. This was identified within the results, discussion, and implication sections of articles, with a position established that research provided an appropriate platform to explore this topic. Whilst not focused on social navigation strategies, other themes that emerged, such as social scripting, may have indirectly contributed to our understandings. Through thematic analysis (Braun & Clarke, 2006), there appeared to be a large focus upon the scoring in various domains of tests used, for example, the dimensions of daily stress. There was a limited focus upon what these meant, and what these findings represented within real life, as opposed to directed social and observational encounters. Tools used in included articles were highlighted through the charting process, however, these were not always acknowledged in the aims of the articles. Overall, it appeared that measurement tools were to facilitate data collection to meet the research aims of the study, rather than evaluating the tools themselves. The use of a statistically ground measurement strategy concurs the focus upon increasing positives. If measurements were made, these were compared to that considered to be '*average*' or of '*normal level*'. Through this, the focus was directed from individual views to the reliance on what is perceived to be desirable. This lack of consideration of the real-life implications of the measurement conclusions is a theme which was underlying through many included articles.

Links between charting and thematic analysis were prominent in the awareness of specific concepts and concepts discussed. Whilst charting sought to measure the citing of these, thematic analysis unpicked these in more detail, specifically in their links to the aims and focus' of empirical studies. A significant link between charting and thematic analysis was found in relation to the samples and effect of gender. Charting identified the predominance of males, whereas thematic analysis put the focus more upon the differences and specific challenges faced by females. A possible

reason for this is the higher number of males that have an autism diagnosis and therefore are more easily accessible to researchers. On the other hand, the thematic analysis highlighted the specific areas where there may be differences between how females present, the challenges they face, and the strategies they employ to progress in their life.

A difference between charting and thematic analysis was found within reporting of concepts. Whilst charting focused upon concepts such as social experiences, mental health, and friendship, thematic analysis focused upon social norms and expectations and their effect on the concepts within charting. The themes and sub-themes identified through thematic analysis contributed to understandings of what the social world includes. After the identification of topics in charting, these were developed through thematic analysis to identify the importance of them.

Camouflaging or masking of difficulties was not significant within charting, whereas it appeared to be a significant and overriding theme within thematic analysis. This consideration mirrors the discussions by Gould (2017), specifically in the differences of external behaviours and internal understandings. Charting identified different methodological approaches to research, however this was not considered as a main theme within thematic analysis. Though, discussion sections of articles provided rich in-depth discussion, where consideration of methodology were more frequently cited.

#### **4.5.5 Links to the literature**

The use of scoping review methodology to explore multi-dimensional topics was a primary reason for it being used (Arksey & O'Malley, 2005; Anderson, Allen, Peckham & Goodwin, 2008). The exploration with this specific review was able to help identify the multiple topics which fall under the theme, as well as identifying the levels on consideration of these in previous literature. The gaps identified in the included articles were identified through the various stages of analysis. Whilst this ability to identify gaps was not unexpected (Munn *et al.*, 2018), the level to which gaps were identified in areas other than methodological design provided interesting future direction.

The validity of the scoping review method and its specific use for this phase is considered high (Pham *et al.*, 2014), however, as limitations of the lack of multi-person agreement are discussed, there remains to be areas in which this could have been improved. Though scoping reviews do not require a critical appraisal of sources (Aromataris & Pearson, 2014; Liberati *et al.*, 2009; Pearson, 2004), factors which would present in this were included in evaluations. The aim to summarise previous works was aided by the extraction of set information from each article (The Joanna Briggs Institute, 2015). An additional use of this method of collation and extraction aided the analysis process and time taken to code the data.

Previous literature findings of the predominance of quantitative approaches and standardised measurement tools were reinforced in this review (Fulton *et al.*, 2017). However, there is evidence that there are efforts being made to include additional approaches bearing qualitative features (Bölte, 2014). Whilst some view the increase in consideration of females to be a recent development, the inclusion of female participants did not show any correlation to the year of publication in the articles included in this review.

As a result of the predominance of considerations of social interaction and communication with diagnostic criteria (APA, 2013), it was not a surprise to find these domains being considered in samples. Though, in this review, it was found that these areas are increasing in complexity as well as presenting how they are experienced within adolescence. For example, the increase in use of technology and social media. Though only a small number of studies directly considered these areas, those that did identified several strategies enlisted on these platforms to limit perception of difficulty or difference. This presents a different perspective than Abel, Machin and Brownlow (2010), as they focused on the functionality of communication and the move to online platforms.

Discussions in chapter two included a consideration of interventions autistic people may be encouraged to engage with social skills training (Gould & Ashton-Smith, 2011). However, as only one article utilised an intervention methodology, consideration about the use of these for autistic teenage girls could not be made. In response to literature highlighting the predominance of male samples, this review presents an emergent

finding linking the gender demographics of included participants to the broad methodological framework employed. Specifically, articles with a majority or over half male sample utilised quantitative methodology, in comparison to qualitative or mixed methods used for all female, mainly female and over half female sample groups.

The body of literature identified prior to undertaking this review on the topic of camouflaging gave some indications of possible findings, specifically that this would be more identified in female populations (Dean, Harwood & Kasari, 2017; Lai *et al.*, 2017). This conclusion was identified within articles in this review, though, an additional consideration of a desire for social inclusion was evident also (Seifert, Hoffnung & Hoffnung, 2000). Challenges in relationships and friendships were found within the review, however, an emergent theme which varied to what was expected, was the difference in perception of such difficulties through the various perspectives included. The rapid growth of the internet was not considered to be representative in the included articles, however, this may be expected due to the limited standardised tools in this domain, and the overall preference for these in included articles. Nevertheless, this analysis has achieved the aim of providing clarity in where the gaps in research can be found.

## **4.6 Discussion**

### **4.6.1 Strengths and limitations of the Scoping Review**

#### **4.6.1.1 Strengths**

This review was able to collect a significant number of publications related to the search sequences defined. The exploration was enhanced through the variety of synonyms used to describe the topics central to the study. In addition, publications were retrieved from both a variety of databases as well as a variety of journals. With a variety of sources, the findings were considered representative of research generally, limiting the bias of a specific aim or model of disability. The strength of the phase lies within the general standardisation of all the procedural and evaluative aspects of the phase. The replicability of the phase is enhanced by the clarity and standardisation, as well as the evaluations of the quality of the findings and conclusions made. In addition, the use of both charting and thematic analysis provided a deeper understanding of previous research, specifically in the findings that methodological

approaches achieved. As a result of the staged process of thematic analysis, the pathway from the data to the themes was clear.

#### **4.6.1.2 Limitations**

Upon reflection of the review, there were aspects that may have been improved upon if replicated. The strength and reliability of the themes may have been enhanced by triangulation and inter-rater agreement throughout the process of data collection, sifting and analysis, as well as increasing scientific rigor. Levac *et al's* (2009) addition to Arksey and O'Malley's (2005) framework for scoping reviews mirrors the awareness that this would enhance the methodology. The financial and time limitations associated with the phase were justification for the single evaluation, nonetheless, using triangulation and independent agreement between at least two researchers would be preferable if this phase were to be replicated.

Whilst every effort was made to identify the desired information regarding samples, it was not always provided in enough clarity to be included within charting. This presents another area that would have benefited from triangulation and inter-rater agreement. It is possible that the reviewer's previous experiences and knowledge base may have influenced the perceptions of the limitations cited. A prominent theme was the limited female sample, which was discussed as being a result of accessibility of female participants. Whilst interesting to consider the reason for this, a full exploration was beyond the scope of this review.

Two of the databases had different methods of inputting search sequences to meet the inclusion criteria, as such, some articles may have been excluded prematurely. The focus upon publications through database searches may have resulted in useful documents from wider sources, such as government and charity reports, being excluded. Through the secondary stage of data collection, removing articles based on title and or abstracts may have resulted in articles being discarded, as they may not have been a fair and accurate reflection of the full content. Whilst this can only be postulated, it further reinforces the preference for triangulation between at least two researchers when using this method.

Overall, limitations focus upon areas which could strengthen the reliability and validity of findings, as well as methodological decisions influencing the articles available to be included in the review.

#### **4.6.3 Recommendations and implications**

Recommendations for future research would be to include articles published in other languages, as the sole inclusion of those in English, may present findings that are culturally specific and therefore unable to be generalised. In addition, conducting a larger pilot study which includes searches in each of the databases to ensure the procedure would be exactly replicated is advisable. Using sources other than those rooted in academia may ensure that the scope of the current understandings of the topic area are fully represented through various domains, for example reports published by non-governmental organisations. Whilst a trial was undertaken to ensure familiarisation with the technological aspects of database searches, additional training and awareness of their functions may have aided the smooth running of data collection. Terminology to be included within the search terms were thought out and discussed, the phase may have benefited from further time spent to design these terms, for example, including a consultation with external advisors. The sixth stage of a scoping review, consultation (Arksey & O'Malley, 2005), was not employed in this phase. Though it may have been beneficial to organise the themes for significance and importance for a range of stakeholders.

Whist charting is likely to be influential in the methodological design of future study, thematic analysis provided a wider consideration of possible influences as well as findings achieved in previous research. Findings from this review can be applied in the future practice in relation to research being conducted. It has provided an overview of the main themes of the previous research in the field, as well as identifying areas which may not have explored. It has provided a clear awareness of current gaps which can be addressed in the methodological design of future studies, as well as the inclusion and exclusion are participants. Through the themes identified, it provided a basis for not only research, but for clinicians who work with individuals with, or being referred for a diagnosis of autism. The decision to enlist this methodological approach

to review previous literature was a result of its ability to source previous literature to inform decision making. As such, this was the main implication upon its completion. Any other implications were not a driving force during the planning stages.

Through conducting this review, it helped define the concept of, and topics included within the term 'social world'. In addition, it provided some direction and possible areas where the navigational strategy employed by individuals may have measurable and reported impacts. The primary justification for the completion of this review was to inform the design and contextual framework for a future empirical phase. Therefore, the themes identified facilitate the development of a methodological framework which seeks to answer or clarify previously identified questions in the field of gender and autism. They also provide guidance as to possible difficulties or barriers which may be experienced when designing studies using samples mirroring many the articles included in the review.

The primary gaps highlighted in this review were the lack of autistic voices included in the articles. All of the articles included identified clear aims and objectives, though, these autistic voices were not demonstrated to have been consulted or considered when identifying the research priorities and aims. Specifically, in articles where autistic voices were sought, they were in response to a designed measure or self-report tool (for example, article 7, Bauminger *et al.*, 2008 and article 14, Chamberlain, Kasari & Rotheram-Fuller, 2007). Cridland *et al.*, (2014, article 20) utilized direct quotes from autistic people and parents, therefore presented some autistic voices as opposed to reducing these through statistical analysis (for example, article 12, Cage & Troxell-Whitman, 2019).

An additional gap highlighted was the real-world implications of the research being conducted, specifically, articles presented findings, but did not include their purpose for informing practice or aiding understanding of autistic teenage girls' needs. Finally, the reliance on traditional quantitative and qualitative data collection tools was identified as a contributing factor to the topics included and the limited inclusion of authentic autistic experiences across the lifespan.

This first phase has framed the topic area, narrowing down the focus, whilst also contributing to the methodological design of the following two phases. As this scoping review focused upon a professional domain of academic peer-reviewed literature, an alternative domain, of newspapers was considered appropriate for the next phase. Furthermore, this was aiming to contribute to the gap of the real-world implications of research and organisational practices such as diagnosis. The final phase in this thesis will utilise the themes highlighted in this review to shape the content of the coproduction phase. Specifically, this phase aimed to address the gap of authentic autistic voices by engaging with a range of stakeholders, whilst also utilising a participatory methodology to coproduce data, contributing in an alternative way to the frequently used qualitative and quantitative tools. Through the subsequent phases, the complexity of the social world should not be undervalued but should utilise the themes and sub-themes identified to define the search and inclusion strategies.

#### **4.6.4 Summary of Chapter**

The main finding from conducting this review was that there are clear preferences in methodological diagnosis enlisted by studies in the field. Specially, the preference for standardised tools which can produce statistical significance were highly prominent. In addition, the distribution of the dates of publication documents the increase and focus of the consideration of these topics, in turn, reinforcing their appropriateness in the current day.

With regards to the outcomes for participants included in the studies, overall, outcomes and scores in the various domains tested were lower in samples with autism than their typically developing peers. Nevertheless, the complexity of the various domains measured were evident, and the individuality and variation in experiences was clearly noted. Whilst not all raised conclusions regarding the influence of gender, the overall perception from proxy reports were that females experienced less difficulty and challenges compared to males. An additional interesting finding was that enlisting firsthand accounts did feature in a small number of articles, as well as methodological choices which would be considered participatory.



What is apparent from the review is that the effect of gender is multi-dimensional and should be considered alongside other social and cultural influences. Overall, it reinforces the need to consider on a deeper level the presentations and descriptions given by individuals or their families, rather than taking them on face value. The seven themes, and related sub-themes demonstrate the complexity and vast nature of the topic area. In turn, they provide a summary of the current research base, which can be used when providing rationale for the empirical phase.

## **Chapter 5: Phase two**

### **A FOUCAULTIAN DISCOURSE ANALYSIS OF THE PORTRAYAL OF AUTISTIC TEENAGE GIRLS IN NATIONAL UK NEWSPAPERS**

#### **5.1 The Introduction**

This chapter presents an initial phase of the study that built on the scoping review by exploring how autistic teenage girls were portrayed in UK national news articles in 2015 and 2019. This phase follows on from the themes and findings from the scoping review, using a different output and method to enhance the understanding of the topic area. It is important to acknowledge and understand an additional form of information that exists about autism, newspapers. This contributes to the wider social discourse as a source of information with an alternative perspective and position to academic literature. The two time points used the analysis include a sample from before this study commenced (2015), and a sample in the development stages of this study (2019). This increases the data available for analysis and enables a comparison to be made.

Foucault's principles for conducting a discourse analysis were utilised, as described by Willig (2013), encompassing specific stages to follow. An introduction to previous literature in the area will be presented, along with an account of the procedure, the results of the analysis and a discussion of these results. More information about the discourse analysis method can be found in chapter 4, specifically its selection to contribute to the overall aims of this study.

##### **5.1.1 News as a source of information**

Whilst alternative sources are available, news media is considered a major platform for individuals to acquire information about the world and their community (Prior, 2013; Prosser & McCombs, 2016). When considering how the public may receive information about specific issues, for example disability, the news media represents a highly prevalent source, rather than gaining information and knowledge directly from disabled people (Haller, 2010; Haller *et al.*, 2012). As a result, It may not always reflect people's views surrounding disability or the range of views inherent within society. The ability for the news to inform the public and characterise social issues has long been

discussed, for example within McCombs and Shaw's theory of agenda setting (1972). Agenda setting focuses upon how the portrayals of topics within the media transfer and influence the priorities made by readers on such topics (McCombs & Shaw, 1972). Chong and Druckman (2007) add to this, describing the importance of how topics are framed, and which aspects of this are emphasised or focused upon. More recently, Luo, Burley, Moe and Sui (2019) describe how agenda setting has developed over four decades, which may explain why it is viewed as one of the most important theories within media research.

Arguably an additional function of news media is often translating health and scientific information so it can be understood by the public (Viswanath *et al.*, 2008). Furthermore, Nelkin (2001) describe this in a similar way, describing how the media can frame how the public view reality. The way reporting is framed includes the sources, priorities and the angles journalists focus upon (Wallington, Blake, Taylor-Clark & Viswanath, 2010). Whilst informing the public, news media can tell readers what to think, as well as how to think about and view certain topics (McCombs & Shaw, 1993). More recently Quinlan and Bates (2009) describe the media as having a great influence on how people with disabilities are perceived among society. In addition, when presenting disability activists, the media is considered to exclude them, or when they were represented, this often-attracted negative connotations (Haller, 2010). Zhang and Haller (2013) describe how this may contribute to misunderstanding about the issue's individuals with disabilities face.

Theoretical frameworks can be seen to support the influence media has, specifically, Bandura's (2001) Social Cognitive Theory (Zhang & Haller, 2010). This proposes that consumers of media reflect and learn from the topics discussed, rather than being passive viewers of it. When considering one's developing self-identity, frequent media consumption may result in consumers internalising their observations, further influencing their own values and beliefs (Zhang & Hallar, 2010). For example, frequent exposure to media which shares unrealistic female body images negatively affects young girls' self-perception and lowered their self-esteem (Clag, Vignoles & Dittmar, 2005).

Before the arrival of online sources of media, there were considerably fewer media sources available for people to engage with (Feezell, 2018). Though, these were able to reach broad audiences and subsequently influence opinions of topics discussed and the prioritisation of presented topics (Feezell, 2018). In comparison, the media environment when writing this thesis (2018-2021) encompasses more media sources, allowing for tailoring to specific groups' interests of agenda's, which may challenge how the media can shape the public agenda (Chaffee & Metzger, 2001; McCombs, 2005; Prior, 2007; Williams & Delli Carpini, 2011). Agenda setting and the public agenda at any given time has wider implications for policy makers and ensuring accountability (Feezell, 2018). The policy agenda has been defined as the 'list of subjects of problems to which governmental officials...are paying some serious attention at any given time' (Kingdon, 1984, p.3). Linking back to the role of the media, the policy agenda is shaped by the value of importance placed on issues by the public (Feezell, 2018). Public belief is increasingly influenced by the mass media, with decisions made by publications as to which and how topics are presented having consequences of how the issues are viewed by the consumer (Iyengar & Kinder, 1987; Price & Tewksbury, 1997; Scheufele & Tewksbury, 2007).

### **5.1.2 Portrayals of autism in the news**

Frustration with how autism is portrayed in Australian media has received attention among academics, for example, Jones and Harwood (2009) outline the portrayals of people who have an autism diagnosis to be problematic. Specifically, they describe how positive characteristics were rarely featured, with medical models dominating the included articles with a likely influence of stereotyping 'autism as problem' (Jones & Harwood, 2009, p. 15). Similarly, Huws and Jones (2010a) identify the role of language choices in reinforcing this position, for example, suggesting that people 'suffer' from autism (p. 102). Overall, presentations of autism were standardised and homogenised, which may perpetuate stereotypes and assumptions about the label (Huws & Jones, 2010a).

Understandings of disability can be extensively influenced by portrayals in the media (Haller, Dorries & Rahn, 2006), which further reinforces the discontent with limited research in this area (Jones & Harwood, 2009). More recently, Goethals *et al.*,

(2020) describe how the growth in research within disability studies has not transcended to the area of media, considering publications to be lacking. Should the wider context of the evidence not be provided, individuals may not fully process all the evidence, thus being unable to make an accurate determination (Jensen, 2008; Jensen, Moriarty, Hurley, & Stryker, 2010; Huws & Jones, 2010a). Stigma surrounding mental health and disability may be increased through the platform it gets within news media (Huws & Jones, 2010a; Holton, Farrell & Fudge, 2014). On the other hand, journalists have the opportunity through their platform to challenge representations and enhance knowledge (Hinshaw, 2007; Sartorius & Schulze, 2005). The awareness that news media provides a platform for topics to be discussed is not new, with Coverdale, Nairn and Classen (2002) describing the lack of analysis in this area as being problematic.

News media provides a source of health information for the public, which can include vaccine safety issues (Vasterman, Yzermans, & Dirkzwager, 2005; Huws & Jones, 2010b; Freed, Clark, Butchart, Singer & Davis, 2011). A specific example is the contested relationship between autism and the MMR vaccine (Jones & Harwood, 2009). Whilst scientific studies have not found a link (Gerber & Offit, 2009), news media and its falsely balanced information shared is likely to have contributed to the public uncertainty (Speers & Lewis, 2004). Interestingly, it has been suggested that a hypothesis which demonstrates a clear scientific consensus may result in higher news media disagreement (Boykoff, 2007; Dixon & Clarke, 2012).

### **5.1.3 Portrayals of disability in the media**

Reviews of the presence of disability related content within mass media has identified an increase in reporting (Briant *et al.*, 2011; Yu & Farrell, 2020). In addition, a change in the way disability is positioned within reports accompanied this (O Malley-Keighran & Coleman, 2014). This change included a reduction in publications of lived experiences as well as sympathetic or equal terms (O Malley-Keighran & Coleman, 2014).

Models of disability have been outlined within academic settings (see 2.7.4 for discussion), with similar models being found to be in use within the media (Zhang &

Haller, 2013). Clogston (1990) outlines three models found in the media: the medical model, the social pathology model and the supercrip model, which all focus on how media frames people with disabilities and the experiences they face. Like the medical model discussed previously, within media framing, it portrays individuals to be reliant upon health professionals for support, as well as requiring a cure (Clogston, 1990). The social pathology model portrays disabled people as being disadvantaged, with support being required from society and their communities (Clogston, 1990). Drawing upon the ideas of this model, Quinlan and Bates (2008) identify how depictions of disabled people may result in views that disabled people take advantage of their label to gain privileges or alternative accommodations, which would not otherwise be available. The final model Clogston (1990) outlines is the supercrip model, where individuals who achieve success or live what is considered a normal life, are represented as having superhuman capabilities. These models have been added too, for example, Haller (2000) introduced the legal model, positioning certain treatment of disabled people as illegal. They remain to be used in academia to highlight the models of disability in the media. Haller and Zhang (2014) describe these when evaluating the media perception of disabled people through disabled people completing an online questionnaire.

Kama (2004) describe the term 'supercrip' as being applicable in two situations. The first, when an individual with a disability achieves in daily life on par with their peers, and the second, where people excel beyond expectation for all of society (Silva & Howe, 2012). These situations equally portray the disabled person described as heroic for achieving what was not considered possible, due to the label of disability (Hardin & Hardin, 2004). Drawing links with the stereotypes attached to disability, Silva and Howe (2012, p.178) describe the supercrip model as a "narrative displaying the plot of someone who has 'to fight against his/her impairment' in order to overcome it and achieve unlikely 'success'". In a study by Burns (2016), language choices to describe disabled people often included 'inspirational' and 'inspiring' in the context of journalist students, despite being informed of how these terms perpetuate stereotypes.

#### 5.1.4 Ableism and stigma

Disability studies are positioned as the opposite of deficit-based understanding of disability and are positioned as a marker of identity in a multidisciplinary context (Connor, Gabel, Gallagher & Morton, 2008; Vale & Connor, 2019). Ableism has been identified as a concept that is applicable in disability studies (Bogart & Dunn, 2019). Campbell (2001, p.44), provides a definition of ableism that reinforces disability being considered a less desirable or worthy state of being. Specifically, this cites how:

*“ableism refers to a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human”* (Campbell, 2001, p.44).

Ableism side-lines social influences within disability, resulting in difficulties being treated as “naturally horrible”, and the diagnosis providing an explanation and source of blame for the problems experienced (Amundson & Taira, 2005, p.54). In addition, it generally is a form of social oppression, compared to the individual or specific discrimination identified under definitions of disability (Jun, 2018). Whilst ableism is considered a concept, it also fits within the wider understanding of stigma, being represented within the literature (Bogart & Dunn, 2019).

Theories of stigma outline three functions it presents, the first, exploitation, the second, enforcing social norms, and finally, avoidance of disease or illness (Phelan, Link & Dovidio, 2008). Research that explores the stigma experienced by certain groups has identified that encountering stereotypical assumptions, discrimination, and prejudice, can result in these being internalised (Earnshaw & Quinn, 2012). The results of this stigma can lead to individuals coming to anticipate that level of stigma and prejudice across society (Earnshaw & Quinn, 2012; Feinstein, Goldfried & Davila, 2012). In addition, this has been linked with negative health outcomes and distress, though a full analysis of these affects is beyond the scope of this review (Feinstein, Goldfried & Davila, 2012; Hatzenbuehler, Nolen-Hoeksema, & Dovidio, 2009).

Within discussions of ableism amongst society, links are drawn to the process described as the insider-outsider distinction (Dunn, 2015). This process outlines how disabled individuals, or insiders, know what disability is like, whereas the wider society, those without disabilities, make judgements based upon ableist assumptions (Dunn, 2015). These assumptions may be that disability is inherently negative, with a continual affect throughout one's life (Dunn, 2019a, 2019b).

Experiencing ableism appears to be common among disabled people, however it is not always viewed as problematic or unacceptable (Bogart & Dunn, 2019). This considered, a representative sample of individuals across 32 countries associated experiences of ableism with a deterioration in health and well-being (Branco, Ramos & Hewstone, 2019). Within this study, ableism was considered alongside other concepts such as racism, ageism and sexism, and their consequences on health and well-being.

### **5.1.5 Autism and stigma**

Society's curiosity about physical and mental disability may encourage information to be disseminated through mass media and news (Bailey, 2011; Broderick, 2010; Ellis & Goggin, 2015). The information which is provided supports individuals in developing their own views and beliefs, which they may not otherwise encounter (Amoako *et al.*, 2019; Bailey, 2011, Broderick; 2011). Whilst the coverage within media sources may help discovery of previously unknown topics, there remains the risk of stigma arising from the way disability is depicted (Darke, 2010; Falk, 2001). The rise in media coverage of autism and related mental health difficulties should be celebrated with caution (Broderick, 2010), as portrayals focusing upon isolation, challenge, and burden on others, reinforce negative views (Waltz, 2012). Holton, Farrell and Fudge (2014, p.191) extend this, stating that the current media accounts and portrayals may be "doing more harm than good".



Inzlicht and Good (2006) describe how stigmatisations helps create platforms that tolerate the devaluing of individuals, coining these as “threatening environments” (pp. 129-131). Disability discourse on a broad level has been tainted by negative connotations and associations, in turn compelling views of individuals, for example those who identify as autistic, as different, rather than promoting inclusion (Stuart, Arboleda-Florez & Sartorius, 2012). Viewing individuals as being different though focusing on difficulties, serves to marginalise them from society as well as generating discrimination (Coleman-Fountain, 2017; Ginsberg & Rapp, 2010; Holton, Farrell & Fudge, 2014).

Focusing on traits that individuals possess which deviate from social norm, not only provoke separation, but draw upon the negative connotations to create stigma (Holton, Farrell & Fudge, 2014). This closely aligns with the broad definition of stigma, through the focus on deviating from the norm and the use of deficit driven descriptions (Falk, 2001; Stuart, Arboleda-Florez & Sartorius, 2012). Stigma may be conveyed through labels, discourse, or physical experiences, any of which place shame on the individual, which lasts considerably longer than the experience, often a lifetime (Hinshaw, 2007). In 2001, Powell described how stigma surrounding mental health difficulties may often begin in a subtle or un-noteworthy statement, with major events or a rise in public discussion being the catalyst for the presence in far reaching news media. An example of this follows the publication of false findings indicating a link between autism and the MMR vaccination (Wakefield *et al.*, 1998). This created unease among parents, thus increasing news coverage (Clarke, 2010). Whilst the study has subsequently been retracted due to falsification of data and findings (Holton, Farrell, & Fudge, 2014), the effects prevail as demonstrated by reports that the public still view the link as being present (Huws & Jones, 2010b), and possibly the reduced uptake of MMR vaccination rates and increased cases of measles and mumps (CDC, 2011; Godlee, Smith & Marcovitch, 2011).

The focus journalists use within news media is on the science surrounding disability, with other professionals' thoughts and contributions prompting generalisations to be made (Murray, 2008). Critiques from public health officials (Dorfman, Wallack, & Woodruff, 2005) and academics (Higgins, Naylor, Berry, O'Connor, & McLean, 2006) often focus on how these artificial representations rarely provide a contextual

focus that society can appreciate or relate too. Providing a platform for the perspectives of individuals with a disability is rare, with secondary accounts from family, or other public bodies being more common (Holton, Farrell, & Fudge, 2014).

#### **5.1.6 News framing**

In an analysis of 198 autism themed articles from the New York Times, the medical model of disability was dominant, with around 12% portraying views of inclusion and neurodiversity (Billawalla & Woblring, 2014). In addition, medicalised language was identified in a review of British news, with specific references of individuals being victims, and suffering because of autism (Huws & Jones, 2010a). The content of articles included in reviews varies, for example, McKeever (2012) identified possible solutions or remedies in 48% of the articles, and the possible causes of autism in 35%. Following on from the theme of causation, Robertson (2009) found articles more frequently postulated medical rather than social causes.

Depictions of autism feature across various media, with illustrations of autism and its characteristics being included in television and film productions (Holton, Farrell & Fudge, 2014). Whilst they have been credited as having increased awareness of the diagnosis, there lacks an equal impact on decreasing the stigma associated with the diagnosis (Broderick, 2010; Holton, 2013; Holton *et al.*, 2017). Depictions in these domains typically rouse feelings of shame or pity for characters, without displaying their views and experiences (Holton, Farrell & Fudge, 2014). This approach is considered to lack the potential to widen knowledge about autism and wider diagnoses (Moody, 2011; Murray, 2008). Journalists also present a unique position in influencing public awareness and perceptions, specifically those working for the news media (Holton, Farrell & Fudge, 2014). Over the last few decades, these have typically focused upon the cause of difficulties, the aim of finding a cure, most notably, purported links between vaccinations and receiving an autism diagnosis (Clarke, 2010). This lack of balance has been viewed as a criticism of the news media, with placing blame being promoted, as opposed to challenging misinformed concerns present among society (Clarke, 2010; McKeever, 2012). It is worth noting that whilst studies exploring the portrayal of autism in news media have been undertaken, the majority examine the tools journalists use to discuss autism, for example, news

framing, rather than the representations and positions these journalists display through an article's narrative (Holton, Farrell & Fudge, 2014).

News framing has long been defined as a central idea or storyline that "provides meaning to an unfolding strip of events, weaving a connection among them" (Kang, 2011, p. 246). Events, issues, and actors are the forms that news takes place (Entman, 2004), with every news story having its own central themes and ideas (Dimitrova, Kaid, Williams & Trammell, 2005). To give a news item an "identifiable slant", specific angles or findings are highlighted and made more prominent, with other items being discounted or downplayed (Block-Elkon, 2007, p.25).

These components are knowingly selected by journalists to communicate information to consumers in an accessible and understandable way (Holbert *et al.*, 2005; McCombs, 2004; Shoemaker & Reese, 1996). Furthermore, these frames provide meaning to the narrative being presented, drawing connections between events using new information and contributions from wider sources (Holton, Farrell & Fudge, 2014).

Following on from the overall news framing, issue framing identifies which specific issues or themes within the topic area will be included in the produced media (Kang, 2011). The way in which news framing in health-related disciplines can be analysed focus upon the issues discussed within published media (Kang, Gearhart, & Bae, 2010). Within news in the field of disabilities including autism and ADHD, patterns have been identified. Probst (2006) described how analysis supported findings that symptoms were the significant topic. On the other hand, Wilkinson and McGill (2009) found personal stories, education and services were the significant issues in British newspapers. Much work has been done to outline topics considered in news media, which include diagnosis, intervention, therapy, cause, legal cases, personality, and government policy (Clarke, 2008; Sigman, 2007; Speers & Lewis, 2004; Splittler, 2009; Douwe, 2009; Riggott, 2005; Kitzinger, 2000). Whilst an in-depth discussion of each of these is beyond the scope of this analysis, it provides an awareness of the variety of topics previously identified and helps to situate this analysis among other literature. The coverage of topics related to autism in magazines again provides evidence issue framing, as general audience publications placed more

emphasis on research findings, and those targeting a female demographic focused on dismal outcomes and the desire for improvement (Clarke, 2011). Supporting the issue being prepared for publication, news media selects accompanying sources to ensure knowledge can be gained from and it is viewed as credible (Kang, 2011).

## **5.2 Method**

This section provides a summary of discourse analysis, followed by an explanation of why Foucault's approach was chosen. This approach, as outlined in Willig (2013), guided the method in this specific analysis. Consideration will be given to the search strategy, data inclusion and retrieval, as well as the analytic framework used.

### **5.2.1 Research questions and objectives**

The research question for this analysis was: How are autistic females portrayed in news articles? This was influenced by the literature identified in section 5.1 that focuses upon the media in addition to the wider thesis aims that identify autistic females as being the population being explored.

The objectives were:

- To consider the context in which the articles are published and the impact of this on how autistic females are viewed or portrayed in the media.
- To consider the language used to describe autistic females and the characteristics or behaviour associated with this.
- To consider how wider concepts, such as models of disability, and societal perceptions of autistic females can be identified in this discourse analysis.
- To identify and evaluate the sources used within articles to provide quotes or accounts about gender and autism, specifically in females.

### **5.2.2 Discourse analysis background**

The emergence of discourse analysis provided an alternative methodology to explore social reality, as many social scientists were dissatisfied at prior quantitative methodology grounded in the positivist paradigm (Bilic & Georgaca, 2007; Gergen,

1985; Potter & Wetherell, 1987). 'Discourse analysis' was first described in 1952 by Harris and defined it as a way of analysing writing and speech (Harris, 1952 cited in Kaplan & Grabe, 2002). Two main interests surrounded this definition, which were the examination of language, and relationships between linguistic and non-linguistic behaviour (Paltridge, 2012). The second interest is described as understanding how people know, within that specific context, how to interpret meaning and any action required (Paltridge, 2012).

The social constructionist paradigm that underlines discourse analysis views social functioning as being produced through interactions, influenced by social, cultural, and historical contexts (Burr, 1995, see chapter 3 for a detailed discussion). The scope of this paradigm includes everyday interactions, institutional practices, and scientific developments, with it focusing on how aspects of social reality are constructed, challenged, and disseminated (Bilic & Georgaca, 2007). Psychological processes are investigated within this approach, specifically the implications these have on individual experiences (Nightingale & Cromby, 1999). An example of this is identity, which is described as a process that develops in response to the persons history and social experiences (Burr, 1995; Billig, 1995).

#### **5.2.2.1 Discourse analysis variations**

The prevalence of discourse analysis has increased, though this does not necessarily translate into an agreed approach and definition of discourse among scholars (Cheek, 2004). Discourse analysis has been described as an umbrella term, as it has been used across a wide variety of disciplines for various purposes (Mills & Birks, 2014). For example, it has been used to study language use in certain communities (Mirivel, 2008; Tracy & Ashcraft, 2001), as well as exploring socially constructed meaning and beliefs within society (Nahon-Serfaty, 2012; Wodak & Fairclough, 2010).

There are various approaches to the study of discourse, for example, discursive psychology and critical discourse analysis, with an array of literature available (Anderson & Holloway, 2020). Developed in the 1990s discursive psychology posed questions to conventional thoughts, shifting focus onto how these are interpreted inwardly in one's attitudes, beliefs, and memories (Billig, 1997; Parker, 2004; Edwards, 1994; Hepburn & Wiggins, 2007). This view of discourse implies that

psychological concepts are constructed as action-centred and culturally specific (Hepburn & Wiggins, 2007, p.11). Overriding all stands of discursive psychology is the importance of non-linguistic features and non-verbal cues that accompany the discourse (Glynos, Norval, Howarth & Speed, 2009). The focus on naturalistic data amongst discursive methods was the main reason it was not enlisted in this phase, as it would not have been the best fit for the aims and wider research questions. The conceptual framework is discussed in depth in chapter three.

Critical Discourse Analysis (CDA) can be described as a recognisable approach to language study (Wodak, 2011). As with other approaches, there are numerous variations of CDA, for example initial approaches by Fairclough (1985), and the “sociocognitive model” epitomised by van Dijk (1991). The consensus across these variations is that there are two central elements. The first focuses upon power and ideology within society, and the second interested in the contribution of language to these concepts (Breeze, 2011). This has also been described as a relationship between language and power, including inequality and dominance (Breeze, 2011). There have been close links drawn between this and Foucault’s ideas, however, the structured method associated with CDA is where they diverge (Breeze, 2011). This structured method is the reason this approach was not used, as it was viewed as being more aligned with positivist beliefs (Harwood, 2000).

Discourse analysis informed by Foucauldian theory seeks to avoid the substituting truths and recognises that there is not one truth or absolute position, thus, a fully detached process is difficult to complete (Wetherall, 2001). Intrinsic to the method of discourse analysis is an understanding that language represents social and cultural processes, norms, and values, therefore examinations consider how power operationalises in the construction of meaning (Smith & Bell, 2007).

Within the social sciences, study has been focused on and around three areas;

1. “Social interaction – concerned with talk and communication and what people do with language.
2. Minds, selves, and sense-making – concerned with construction of identity, making sense and the emergence of forms of mind and of social actors.

3. Culture and social relations – concerned with historical and institutional features of discourse and how meaning has shaped over time through processes.” (Wetherell, Taylor & Yates, 2001, p.5-6).

#### **5.2.2.2 Chosen variation**

This phase enlisted the Foucauldian variation as described in Willig (2013). Foucault’s work is viewed as a theoretical position with potential to be used as a method, as such, it does have a prescribed system for its use (Kessl, 2007). A range of methods can be ascribed to Foucault, though they all rely on the researcher’s interpretations, that have formed through their understanding, to generate new questioning and exploration (Potter & Wetherell, 1987; Wiggins & Potter, 2008). This considered, Foucault did provide a definition of discourse, which focused on written or spoken communication can actively contribute to how knowledge and the social world are constructed (Foucault, 1970).

This approach emphasises concepts of power and agency (Mills & Birks, 2014), as well as how this is operationalised within social settings (Wodak & Meyer, 2009). In addition, it has contributed to highlighting and understanding connections between power and the social world (Gutting, 2005). Discursive agency focuses upon how actors, for example journalists, make themselves an agent within the given discourse (Winkel & Leipold, 2016). This is achieved through their decisions of whether, how, where, when they identify with or comment upon the storyline in aligning with specific positions (Leipold & Winkel, 2013). However, Winkel & Leipold (2016) describe how actions can only perform agency if they take a position offered by the discourse.

Foucault’s approach of examining discourse enlists questioning of how power operates, and its role within social construction of knowledge, social norms, and subjectivity (Hicks, 2004; O’Farrell, 2013; Schrifft, 2006). Wodak and Meyer (2009) provide a synthesis of what power means within the field of discourse analysis:

*“Power is about relations of difference, and particularly about the effects of differences in social structures. The constant unity of language and other social matters ensures that language is entwined in social power in several ways: language indexes and expresses power and is involved where there is*

*contention over and a challenge to power. Power does not necessarily derive from language, but language can be used to challenge power, to subvert it, to alter distributions of power in the short and the long term. Language provides a finely articulated vehicle for differences in power in hierarchical social structures.” (p.10)*

This approach seeks to encourage new ways of thinking about events, through alternative conceptions of knowledge, leading us to consider how and why are things are the way they are (Foucault, 1983). In addition, it aims to identify how people construct objects and subjects, considering historical contexts, rather than assuming prior understanding (Willig, 2004). Anderson (2003) also focuses on assumptions people make, specifically, when they assert view of acceptability, or unacceptability. As a result, it is an appropriate choice for the current investigation.

Analysis which enlists Foucault's principles positions meaning and knowledge as being in part, socially constructed (Potter, 1996). Therefore, as Berger and Luckman (1991) describe, there may not be a single truth or right view of what is considered reality. Whilst it may be assumed that discourse analysis is solely considering linguistics, Foucault's position establishes the need to investigate the systems of meaning that operates within language and text whatever the intentions of that discourse are (Georgaca & Avdi, 2012). Considering the context that the discourse was created may help to identify the viewpoints within that specific area, as well as focusing on what factors have constructed or influenced that view (Georgaca & Avdi, 2012).

### **5.2.3 Social constructionism, epistemology, and ontology**

Foucauldian discourse analysis presents an epistemological and ontological position to understand these, Willig (2013, p.138-139) responded based on three questions, which will be discussed in turn:

- “What kind of knowledge does FDA aim to produce?
- What kind of assumptions does FDA make about the world?
- How does FDA conceptualise the role of the researcher in the research process?”



Within discourse analysis, there are some unique terms used, an understanding and definition of these is important for the comprehension of the approach as used within this phase. The term “discursive object” is used within this phase, though, alternative phrasing has been noted in other publications, for example, ‘objects of discourse’. Discursive objects are the words we use to describe things, with analysis aiming to examine the relationship between them (Graham, 2011). This can include asking questions of how words used end up producing what we speak, and what influences these ways of speaking (Graham, 2011).

## **5.2.4 Data sources**

### **5.2.4.1 Database – Lexis®**

Lexis® is a database with a specific area assigned for newspaper articles. The scope of this section included 19 UK National Newspapers (broadsheet and tabloid), and 53 UK Regional (see appendix 5) Newspapers. For this analysis, searches only included the National Newspapers, as the aims focused upon the UK, rather than a specific region or area. Through the database, criteria to narrow down results was accessible, for example, date of publication. There was an option to restrict results using the “industry” categories, for example, technology, construction, and health care. However, due to the multidisciplinary nature of autism studies, this feature was not considered appropriate. Using a database formed much of the planning and protocol writing stage of this phase, both which databases to use, and whether to enlist more than one. An exploration of other databases, for example International Newsstream®, was completed, noting the breadth of coverage and accessibility, as well as the features of them to help produce data to meet the research objectives. As the alternative databases searched for material in the same publications as Lexis®, using more than one would increase the time associated with searches, with likely the same results. Furthermore, International Newsstream® did not have the ability to highlight publications in national newspapers, whereas Lexis® did.

#### **5.2.4.2 Searches and process of locating, Inclusion & exclusion**

The search strategy for this analysis focused upon retrieving newspaper articles from the database Lexis®. Scoping of the database was undertaken prior to full data collection to explore possible search terms and the Lexis® used within articles written for non-academic audiences. Lexis® was accessed prior to full data collection to ensure that search terms and phrases would produce appropriate results. It was noted that these search terms would be more generic, rather than specific search sequences. They included a root word or phrase related to autism, and another term relating to gender. Whilst the database had the ability to include more specific search terms, it was felt that this may in fact limit the analysis. This was a result of an exploration of these search terms in the database and pilot style search that was completed. Whilst the broad terms used in the pilot yielded many results, the majority were quickly excluded after reading the title or introduction.

When collecting data, specifiers were used, namely those which defined the location of publication and newspaper. These were national newspapers, which included a total of nineteen publications. Adverts and promotional materials were excluded, as this type of data was considered to present various discourses and influences that would not be aligned with the research questions.

#### **5.4.2.3 General context, when, sites,**

Searches were carried out at two time points, with the method replicated. The first timepoint was 2015, with articles published from 1<sup>st</sup> January until 31<sup>st</sup> December being included for consideration. The second timepoint was 2019, with the same date bounds being stipulated for inclusion.

The reasoning behind using the Lexis® database was because of its ability to identify appropriate articles from a variety of newspapers, through its dedicated news section. Prior to commencing data retrieval, search terms and phrases were identified. These were used within Lexis® and the results were exported to Mendeley. The terms focused upon autism, and related terms, and a reference to gender within the same

paragraph. The reason for not including a gender marker more closely to the autism term was due to findings in the pilot that this restricted data being included to that which explicitly cited it as a topic or theme. Foucault's framework highlights the importance of explicit and implicit meanings, which further supports this decision. Through allowing for gender terminology to be within the same paragraph allowed a balance between including explicit and implicit meaning, without overwhelming the lone reviewer with results. The sequence with gender specifiers was replicated in each search.

A checklist was created so that the search sequences and restrictions selected were replicated in each search. Including;

1. Selecting UK national newspapers
2. Date published.
3. No duplicates
4. Completing the search term as written in table 10

Table 10 displays the searches that were undertaken, as well as descriptions of the shortcuts. It is worth noting that Lexis® automatically searches for plurals, rather than searching for each separately.

Search term	Gender specifiers
Autism	w/p wom*n OR girl OR female
Asperger's	
"Asperger's syndrome"	
Autistic	
"Autism Spectrum"	
"Autistic Spectrum"	
ASD	
ASC	
W/p	Within the same paragraph
" _____ "	Searching a phrase as a single unit
*	Allows for this letter to be replaced with others

*Table 10: List of search terms and gender specifiers.*

In addition, a record of the number of results and article detailed were collated using Microsoft Excel. Within this document, article descriptions included some key information, for example, their date and the publication they featured in. Once data collection was completed, duplicate results were removed, and the excel document updated. This excel document was used throughout the refinement process to document the articles excluded at each stage, as well as a summary for this.

For this analysis, articles will have to meet the inclusion criteria. No exclusion criteria were defined, as exclusion of an article would occur if it did not meet the inclusion criteria. The inclusion criteria were defined prior to commencing searches. Initial decisions about an article meeting the inclusion criteria were made on the information available from the search method, namely the title and date of publication. To be included, articles had to be:

- Published in the English Language.
- Published within the date restrictions.
- Accessed through Lexis®.
- Able to be viewed in their entirety.

To obtain the article for analysis, several stages of refinement were undertaken. Each stage has been outlined in turn below.

Stage 1 involved conducting each of the searches on Lexis®, recording the number of results on the excel document. Then, the titles of each result were read, with those considered unsuitable being excluded and the remaining articles exported to Mendeley. Within Mendeley, exported search results were categorised into folders for each search term to ensure that removals from each search could be recorded. Stage 2 involved culminating the articles from all searches into a single folder and removing any duplicates. Again, the excel document was updated with the number of duplicates removed. The third stage involved a re-reading of the article title, any subtitles, and the introductory paragraph. It was checked that they met the inclusion and exclusion criteria and research objectives. Exclusions were recorded and updated on the excel document. Articles which passed this stage of refinement were transferred to a new folder, so that they were easily accessible for the next stage of refinement. Stage 4

commenced by reading each article in their entirety. Then, they were re-read with a focus on whether they met the aims of the phase, as well as their ability to contribute to the phase. Unsuitable articles were excluded and the excel document updated. Like previous stages, a folder containing the included articles was updated, ready for the final stage of refinement. The final stage of refinement involved reading through the articles in full again, focusing upon the sample, or group described in the articles. Along with this, consideration was given to the way that it could contribute to the analysis and phase objectives. The topic and focus of the article were reviewed alongside pre-defined areas resulting from previous literature and the researcher's own experience of the field. These topics included: female specific experiences of autism, awareness of autistic females, diagnostic processes, development in the understanding of autism and gender, differences between males and females, and an individual's social experiences. This list was not exhaustive, with decisions about other topics being made on their ability to contribute to the research question and objectives. Unsuitable articles were excluded and the excel document was updated. In addition, the reasons for the exclusion of these articles were noted to allow for discussions with an additional reviewer to consider the included and excluded articles arising from this stage.

Whilst not being attributable to individual stages, overall objectives for the refinement process were outlined. Including;

- Ensuring that the breadth of the analysis was achievable within the allocated time frame.
- Ensuring that the amount of data included in analysis allowed for a deep exploration, keeping in mind the single researcher responsible for conducting the analysis.

#### **5.4.2.4 Sources political context and affiliations**

Whilst not the focus on this analysis, it was important to identify the political leaning of publications included in the search strategy. When reflecting on media publications surrounding a given topic, the role of bias in how coverage is presented should be recognised (Gentzjow & Shapiro, 2010; Larcinese, Puglisi & Snyder, 2011). Depending on a publication's political affiliation or position, the content provided to

readers may vary, with biases inherent in the publication being imparted onto readers (Rembaccussing & Kwiatkowski, 2020). Media organisations frame, construct and shape the information that they publish, which goes against the view of them being a passive transmitter of information (Strömbäck, 2008). For example, media is positioned as an outlet that can influence the attitudes of the public towards vulnerable groups such as disabled people (Reeves & de Vries, 2016).

Bennett and Kidd (2017) provided a summary of the political affiliations of UK National newspapers:

*“The Guardian/Observer (broadsheet, left of centre), Daily Express (tabloid, right of centre), Daily Mail (middle market tabloid, right of centre), Daily Mirror (tabloid, left of centre), The Times (former broadsheet, right of centre), The Daily Telegraph (broadsheet, right of centre), Independent (former broadsheet, left leaning), The I (compact, liberal centre), Daily Star (tabloid, right of centre), The Sun (tabloid, right of centre) and The Sunday People (tabloid, left of centre)” (Bennett & Kidd, 2017: 166).*

### 5.2.5 Analysis

There are varied guidelines of the stages that Foucauldian discourse analysis should follow, for example Parker’s (1992) twenty steps, or Kendall and Wickham (1999) approach that assumes a more advanced level of understanding of the Foucault method (Willig, 2013). The framework this analysis will use is that described by Willig (2013), including six stages to undertake during analysis. These six stages will be described in turn below, and a summary of the key questions within each stage is presented in table 11

Corresponding stage of analysis	Question(s)
1: Discursive constructions	How is the discursive object constructed through language? What type of object is being constructed?
2: Discourses	What discourses are drawn upon?

	What is there relationship to one another?
3: Action orientation	What do the constructions achieve? What is gained from deploying them here? What are their functions? What is the author doing here?
4: Positionings	What subject positions are made available by these constructions?
5: Practice	What possibilities for action are mapped out by these constructions? What can be said and done from within these subject positions?
6: Subjectivity	What can potentially be felt, thought, and experienced from the available subject positions?

*Table 11: Key questions within each stage of analysis – adapted from Vingoe (2008).*

#### **5.2.5.1 Stage 1: Discursive constructions.**

This stage focuses upon the way discursive objects are constructed in each article. These objects were likely to include topics and concepts linked to the research questions, with the overall discursive object of this autistic females. Analysis involved identifying the ways the object is constructed within text, highlighting all references and instances where it is presented. It was important within this stage to include both implicit and explicit references, rather than searching for key words. This draws analysis from lexical comparability to the shared meaning and understanding of the discursive object.

To categorise different types of meaning within the discourses, each category was given a different colour highlighting: explicit meaning was identified with green highlighting, implicit meaning was identified with blue highlighting. This visual method of categorisation then enabled comparison across the different articles.

#### **5.2.5.2 Stage 2: Discourses.**

This stage focused upon the differences between the sections of text identified in stage 1 that present or refer to the discursive object. Through this, these

constructions were located within wider discourses, for example, models of disability.

All included articles were read to identify possible links with wider discourses, with thoughts and interpretations recorded using a coloured pen. Discourses were identified within each article individually to enable discourse frequency to be later recorded. It was found that articles could include multiple discourses with these discourses being identified within several different articles.

#### **5.2.5.3 Stage 3: Action orientation**

This stage closely examined the contexts in which the various constructions are being deployed, with two central questions being asked:

- What is gained from constructing the object in this way at this particular point within the text?
- What is its function and how does it relate to other constructions produced in the surrounding text?

These questions help us to understand what the constructions of the discursive object achieve or portray within the text and is referred to as action orientation. The two questions above were asked throughout reading of each article, with the thoughts and ideas which arose being noted in a different colour pen to enable them to be distinguished from other stages.

#### **5.2.5.4 Stage 4: Positionings**

Following the previous stages of identifying and locating the discourse object within texts, stage 4 focuses on positions they present. The understanding of subject position enlisted within this analysis follows Davies and Harre's definition (1999, p.35), in that it identifies 'a location for persons within the structure of rights and duties for those who use that repertoire'. These positions offer discursive locations where speech and acts may come result, and do not prescribe specific parts to be acted out, which resonate with definitions of roles. Another feature of a subject's position is that it has direct implications for subjectivity. Interpretations and discussions of positioning within



the articles involved notes being made, with post it notes being used to highlight the key positions within each article.

#### **5.2.5.5 Stage 5: Practice**

The key focus within this stage on the relationship between discourse and practice. It requires us to explore the ways subject positions in discourse open or close opportunities for action. Discourse presents a specific version of the world, with the way subjects within them are positioned affecting what can be said and done. This stage also identified when, and how non-verbal actions have a place within discourse.

Overall, this stage of analysis explored and framed the possibilities for action that are within the constructions in text. Within the articles, opportunities for action were highlighted, with them coded as opening, or closing opportunities. In addition, interpretations of the meaning and actions which may result from statements were made in a coloured pen to differentiate from notes from all previous stages.

#### **5.2.5.6 Stage 6: Subjectivity**

This final stage explored the relationship between subjectivity and discourse. Certain ways of seeing the world and certain ways of being in the world are made available through discourse, with them also constructing social and psychological realities. This understanding is supported by Davies and Harre (1999), specifically in that once one has established their own position, subsequent views of the world are based around that position. Furthermore, the positioning in discourse can position storylines and concepts in a way that they are relevant.

Specifically, within this stage, consequences of the subjective positions on participants' experiences were traced. Following from stage 5 asking what can be said or done resulting from different discourses, this stage considered the feelings, thoughts, and experiences from the various positions, and thus, relies on speculation. This stage involved reflecting on the notes and annotations from the previous five stages to identify the likely trajectory and actions result from accessing the article. Overall, this stage speculated how the discursive object

is viewed and may be acted upon, which draws conclusions that can be compared to other articles.

### 5.3 Findings

This section will provide a summary of the findings of the analysis. A summary of the articles will be presented, including their publication, word count and other features. This will also provide insight into wider influences that may have affected the discourse and interpretations. Examples from articles will be used when discussing interesting findings throughout the six stages of analysis which was undertaken. Specific considerations, such as language used, will be considered, and the influence of these, along with the discursive objects on the readers and opportunities for action.

To conclude this section, consideration will be given to other findings which occurred during the analysis, and their relationship with previous literature.

#### 5.3.1 Narrative of refinement (2015)

After the initial results from searches, which including a review of their titles, a total of 93 articles were screened for inclusion. Following the removal of duplicates (refinement 1), 22 articles were included in the second stage of refinement. This included reviewing the title again, any subtitles, the abstract and the introductory paragraph, leading to 16 articles preceding to the next stage. Refinement stage 3 consisted of reading the full article, following by a second read that focused on linking with the aims of the analysis. Again, this stage result in articles being excluded, with 11 articles being included in refinement stage 4. This stage involved a further reading of each of the articles to reflect on the previous stages of refinement. This did not result in any changes being made to the dataset. These four stages of refinement resulted in articles being removed, with a total of 11 articles preceding to the analysis stage.

Table 12 presents the number of articles screened and removed at each stage.

	Articles screened (n=)	Articles removed (n=)
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Refinement 1	93	71
Refinement 2	22	6
Refinement 3	16	5
Refinement 4	11	0
<b>Total included in analysis</b>	<b>11</b>	

Table 12: A summary of the article refinement process (2015).

### 5.3.1.1 Summary of included articles (descriptors)

A total of 11 news article were included within this analysis. Out of these, 3 were published by The Guardian, 2 by the Daily Mirror, with the remainder by 6 publications (Daily Mail, The People, Daily Star, The Sun, The Telegraph, and The Daily Telegraph).

Eight articles cited a specific area in which it was published with 3 citing 'news'. The word count varied across the articles, with the highest being 1312, and the lowest 321. A summary of these characteristics for each article are provided in table 13. The authors will be included and further used to specify which article is being referred to in the remainder of this chapter.

	Author	Title	Date of publication	Publication	Section	Word Count	Geographic location
1	James Tozer	Straight-A pupil, 16, kills herself after being diagnosed with autism	09/01/2015	Daily Mail	N/A	390	N/A
2	Kim Willis	I found my daughter trying to slash her wrists at seven... now she's a beauty queen; ASPERGER'S	13/02/2015	Daily Mirror	News	1220	Northern Ireland

		DIAGNOSIS SAVED CHARLIE'S LIFE EXCLUSIVE					
3	Blanaid Murphy	'Noise of a coin dropping can be 100 times louder for an autistic child. I'm petrified if turbines go up'; Mum's fears at plans to build 150-metre wind farm beside home.	18/04/2015	Daily Mirror	News	632	Ireland
4	Sarah Kurchak	Autistic people are not tragedies. My life has value and joy; autism awareness groups push fear-mongering messages that deny our lives the value they deserve	07/05/2015	The Guardian	Comment is free	581	N/A
5	Zoe Drewett	'It ripped my heart out' Mum outraged after autistic daughter is forced off plane	12/05/2015	Daily Star Online	N/A	430	Original story in USA
6	Marina Gask	The hidden world of girls with autism; As a new documentary and novel address the subject, Marina Gask looks at how schoolgirls mask social disorders	14/07/2015	The Daily Telegraph	Features	1032	N/A

7	Angela Neustatter	'Autism is seen as male thing – but girls just implode emotionally'; they arrive self-harming, or unable to talk. Often they're being dismissed as hormonal. We visit the only state school dedicated to girls with autism.	14/07/2015	The Guardian	Education	1312	N/A
8	Dan Wootton	Inside I'm little and full of fear. I don't want to die and leave my kids; Katie Hopkins shows Dan Wootton She's human exclusive	01/08/2015	The Sun	News	1306	N/A
9	By Telegraph Men	Are you on the autistic spectrum? Take the test; new research based on a simple quiz reveals that men are more likely to be autistic than women. Where do you fall on the spectrum?	04/11/2015	The Telegraph	N/A	360	N/A
10	Geraldine McKelvie	I'm hen picked; Autistic Aimee out of her shell	13/12/2015	The People	Features	321	Northern Ireland
11	Ari Ne'eman	Screening sperm donors for autism? As an autistic person, I know that's the road to eugenics; reproductive	30/12/2015	The Guardian	Opinion	1005	N/A

		technologies are being used to remove people like me from future generations. Who will be next					
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Table 13: Data extracted from articles (2015).

### 5.3.1.2 Overall summary of included articles

Included articles draw on several formats, such as representing real life events, media outlets and wider societal advances in understanding. Included within descriptions of real-life events are experiences autistic people and their families have faced, such as being forced off a plane and being bullied.

A summary of the articles included is provided below to provide context going forward. These feature alongside the citation that will be used through the results, e.g., Gask, 2015.

Citation	Summary
Tozer, 2015	An autistic female died by suicide and the article describes the inquest that had subsequently taken place. Through this, quotes are included from her parents, describing her life leading up to the event and the challenges she faced. Receiving an autism diagnosis was discussed on several occasions.
Willis, 2015	This article includes a retrospective account of an autistic girl's crisis (from her mother's perspective) and the challenges faced. It is then compared with the experiences in the present day which appear more positive, including taking part in beauty pageants.
Murphy, 2015	A mother of autistic children describes the possible impact of a wind farm if it is built near to their home. Direct quotes are included, specifically focusing upon her children's experiences in obtaining a diagnosis and the barriers they face.
Kurchak, 2015	The autistic author describes their own experiences of diagnosis and involvement in awareness campaigns. Such campaigns form

	the narrative of the article, describing the assumptions and challenges embedded within them that have consequences of autistic people's lives. The view of awareness movement is that it is lacking, focusing mainly on deficit rather than valuing diversity.
Drewett, 2015	The overall narrative focuses upon how a family was asked to leave a flight after an autistic girl experienced a meltdown that was considered disruptive. The lack of hot food available was positioned as the cause, with several contributions from her mother. A response from the airline was included at the end of the article.
Gask, 2015	This article is focused upon a book that is written about female's experiences of autism. Quotes from the book's author were included as well as quotes from the girls at the school. The latter half of the article focuses upon academic research and developments in understanding autism in females.
Neustatter, 2015	Beth's experiences in school were described, including the challenges in mainstream provision. The specialist provision which she subsequently attended is described, including quotes from staff there. This goes on to form most of the article. Contributions about autism in females are provided by several academics. The school is involved in a TV programme.
Wootton, 2015	This article describes the interview with Katie Hopkins, with the latter sections (included in this analysis) focusing upon her daughter's autism diagnosis. Her quotes include descriptions of the thoughts when she knew about the diagnosis and the impact on her life.
By Telegraph Men, 2015	This article is focused upon the questionnaire that can identify autism, including encouraging readers to complete it. It includes a quote from the academic responsible for the study. It presents a conclusion drawn from the data so far that men are more likely than women to receive an autism diagnosis.
McKelvie, 2015	This article describes how Aimee, an autistic girl, has gained valuable skills from having a pet chicken. Commentary is

	provided by her parents who reflect on their thoughts when deciding if Aimee could have a pet.
Ne'eman, 2015	This article describes the process of screening sperm donors with the aim of detecting autism. the author provides their own opinions as an autistic person, drawing on the implications of this intervention on wider issues such as sex selection. Context was also provided for the regulations in USA and Australia.

*Table 14: A summary of each article included in the analysis.*

### 5.3.2 Narrative of refinement (2019)

The refinement process for the 2019 searches replicated the criteria used in the 2015 data set. Following the searches and reviewing the titles of results, 98 articles were considered in refinement 1 (review titles), with 73 being removed. Refinement 2 (25 articles, before duplicates removed) condensed the dataset by removing an additional 10 articles. Reading the full article twice formed the third refinement stage (15 articles), where 2 articles were removed. A total of 13 articles were included in the refinement 4 stage (reading each article and reflecting on previous stages), which justified the further exclusion of 2 articles. Through the 4 stages of refinement, a total of 11 articles preceded to the analysis stage.

. Table 15 presents the number of articles screened and removed at each stage.

	Articles screened (n=)	Articles removed (n=)
Refinement 1	98	73
Refinement 2	25	10
Refinement 3	15	2
Refinement 4	13	2
<b>Total included in analysis</b>	<b>11</b>	

*Table 15: A summary of the article refinement process (2019).*



### 5.3.2.1 Summary of included articles (2019)

Key data was collected from each of the 11 articles so that a summary could be produced. These were gathered from five news corporations (Daily Star, Daily Mirror, The Guardian, The Times, and The Telegraph).

	Author	Title	Date of publication	Publication	Section	Word Count	Geographic location
1	Katy Gill	Horror moment 'feral' bullies punch autistic schoolgirl in classroom attack.	26-03-2019	Daily Star	N/A	573	N/A
2	Not stated	Teenager is flourishing while her family get vital respite	02-04-2019	Daily Mirror	News	275	Northern Ireland
3	Claire O'Boyle	The challenge is that girls with autism can be different than boys; World Autism Day 2019 Project focuses on why girls' have special needs	02-04-2019	Daily Mirror	News	372	Northern Ireland
4	Ian Birrell	Greta Thunberg teacher us about autism as much as climate change; The young environmental activist has shown that being different is a gift. But too many people with	23-04-2019	The Guardian	Opinion	980	London

		autism still face cruel treatment.					
5	Amelia Hill	Different for girls: understanding autism; Girls with autism are often misdiagnosed, but a new graphic novel aims to put them in the picture	28-04-2019	The Guardian	Life and Style	1430	London
6	Larissa Nolan	Autism rate hits a high as diagnosis of girls improves	02-06-2019	The Sunday Times	News	429	London
7	Dan Worth	How to identify autistic girls – and what you can do to help	19-07-2019	The Times Educational Supplement	News	1601	N/A
8	Jonathan Leake	Doctors ‘fail to spot autism’ in thousands of girls	08-09-2019	The Sunday Times	News	523	London
9	Rosa Silverman	‘My 16-year-old also addressed the Un’ Carly Jones, MBE	28-09-2019	The Daily Telegraph	News	243	London
10	Ellen Jones	Autistic people are not all superheroes, but we’re not all tragic, either; Until we’re allowed to tell our own stories, others will continue to tell them based on myths and false assumptions	12-12-2019	The Guardian	Opinion	1011	London

11	Florence Leslie	How television is finally waking up to its autism problem	27-12-2019	The Telegraph	TV	1213	N/A
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*Table 16: Data extracted from articles (2019).*

### 5.3.2.2 Overall summary of included articles.

The articles included draw upon topics affecting a wider population, rather than those affecting an individual within a community. There appears to be an increase in awareness of the underdiagnosis of females, which is identified through the titles. This considered, there are some articles that describe specific experiences that an individual has experienced, within the wider topic areas.

To provide context for the reader going forward, a summary of the articles included is provided below. These are presented alongside the citation that will be used through the results, e.g., Leslie, 2019.

Citation	Summary
Gill, 2019	A description of a classroom attack of an autistic girl is the focus of this article. The incident was recorded, and the specific actions were cited for the reader. Autism is positioned as the reason for the bullying through quotes provided by her mum.
NA, 2019	One girl's experience of taking part in the Girls and Autism Project (also described in O'Boyle) is presented, including quotes from family members about the impact it has had. Also, the girl's mother describes the benefit of getting a diagnosis and how the challenges with an autistic child can be difficult. The project is positioned as providing respite for the family.
O'Boyle, 2019	In links with world autism day, the article describes how autistic girls can present differently than males. Information is also given about a Girls and Autism Project and how this has increased understanding of female challenges. The scheme in the 15 months has worked with more than 30 girls in the teenage years.

Birrell, 2019	Greta Thunberg and her influence on the rise of autism knowledge is discussed. Her influence however is described as teaching us about autism and the wider view of difference attracting a negative label. Descriptions of negative life experiences because of being autistic is embedded within the article, further reinforcing the consequences of judgements and stereotypes surrounding disability.
Hill, 2019	Using quotes and discussions from a new novel, this article presents the experiences of autistic females, specifically focusing upon diagnosis. Also, there is a discussion of the current thoughts in the research sector as well as the experiences of the females included in the book.
Nolan, 2019	The level of autism diagnosis was the focus of this article, with the increased recognition of better diagnosis in females being suggested as a contributing factor. Statistics are provided with the number of evaluations carried out in assessments of needs, described as a 21% rise on the previous year and doubled since 2015.
Worth, 2019	Discussing the diagnosis of females in this article draws upon current thinking in the field. Specifically, research is cited and summarised. For example, describing how girls may present differently to males. The key topics, including misdiagnosis are presented in a way that is accessible to the reader, concluding with practical tips for teachers when working with autistic females.
Leake, 2019	The role of diagnosis is central in this article, providing the reader with a background to the difference of identification of autism in females (compared to males). Reasons for the difficulty in identification, camouflaging, is introduced as well as the consequences of going under the radar. This article presents the statistics that show an increase in levels of diagnosis in females, with doctors being the professional described to 'fail to spot' it.

Silverman, 2019	A description of Carly Jones' experiences and her daughter's actions of speaking to advocate for autistic women and girls is presented. This encompasses some of the misconceptions surrounding autism, presenting a balanced view of the strengths and challenges that surround autism. The article is in response to the growing awareness of Greta Thunberg, informing the reader that there are others who are passionately campaigning for a topic or cause.
Jones, 2019	This article draws on mainstream media and public figures to present the narratives that are presented about autism. The overall message is that the mainstream media is not representative as it is guided by how neurotypical people view autism. Embedded in this article are discussions of the disability rights movement, the need for more diversity in representations of autism and the underlying links with an individual's identity.
Leslie, 2019	The author opens this article with a personal narrative surrounding diagnosis and aligning personal experiences to those on the television. Focusing on the show Atypical throughout the article, topics surrounding the construction of autistic characters was central. The use of autistic characters in other shows where this was viewed more positively, linking back to the impact of television on giving autistic people someone they can relate, rather than the perception of what autism 'looks like'.

*Table 17: Summary of each article included in the analysis.*

### **5.3.3 Findings: Analysis (2015)**

#### **5.3.3.1 Stage 1: Discursive constructions**

Each article was read, and notes made about discursive constructions used within the text. The questions identified in section 5.2.1 were used to guide the note making process. For articles by, Willis, Tozer, Kurchak, Ne'eman, Neustatter, Telegraph Men and Gask (2015), the main discursive object within the articles was easily identifiable. In the remaining articles (McKelvie, Drewett, Wootton and

Murphy, 2015) discursive objects presented themselves, however none were the most significant. The lack of significance may be a result of the narrative being constructed on a parent's perspective and interpretation of the storyline, rather than a first-hand account.

As expected, the discursive objects focused on various aspects of autism. Articles by Willis (2015) and Tozer (2015) identified the diagnosis of autism as the discursive object, with Willis (2015) highlighting an equal number of explicit and implicit references (5 each). Similarly, Tozer (2015) included 6 explicit and 6 implicit references to the discursive object. However, whilst the number of references identified in these articles is not vastly different, Tozer's (2015) article has a significantly shorter word count (390 compared to 1220 in Willis', 2015). These discursive objects were similar as they used the diagnosis as an explanation for the events and experiences being described in the article.

Kurchak (2015) had the discursive object of raising autism awareness and training available to do this. Implicit references were more frequently highlighted (N=14), though, the 5 explicit references were used on 4 occasions in the first sentence of a new paragraph, and the fifth, as the concluding comment in the article. A discursive object of screening sperm donors for autism was identified in Ne'Eman's (2015) article, with 9 explicit and 16 implicit references identified. The grouping of these articles was a result of the discursive objects being an action or event that is a concrete and longitudinal.

The discursive object identified in Neustatter's (2015) article was the role of the specialist school and the support provided to the articles subject, Abi. Implicit references to this featured 8 times, with implicit references being highlighted 16 times. Explicit references utilised descriptions of what the school has done to help Abi, "...*the school created an 'emotions ruler' for her with green, amber and red*". The implied references to how the school's helped Abi include descriptions of praise given by other organisations, for example, the National Autistic Society (NAS). Overall, the references highlighted frequently focused upon describing how the school functions, for example, describing its "*fairly traditional academic curriculum*". Within this article (Neustatter, 2015), it is worth recognising that the article describes the school

participation in a documentary to *“help autistic girls’ behaviour to be more widely recognised”*.

Gask’s (2015) article focuses upon a book written about *“the hidden world of girls with autism”*. It should be noted that the school identified as the discursive object in Neustatter’s (2015) article, was the location in which the co-authors of the book received their education. In contrast, the discursive object in Gask (2015) was the book that had been produced, with 7 explicit and 9 implicit references made. Explicit references were voiced by either, the author of the article, or the writing tutor. Alternatively, implicit references presented a wider variety of voices, with direct quotes from co-authors, the headteacher, and the article author. The discursive object focuses on the way the book was constructed, its purpose, as well as the outcomes that may follow, *“it’s a novel that could change lives”*.

An article by Telegraph Men (2015) presents a shorter (360 word) article, with a discursive object of the autism traits quiz. Explicit references featured 9 times, and implicit referenced featured 3 times. Explicit references focused upon describing the *“quiz”* and ways in which it has already been used in an *“experiment”*. Implicit references, however, included a quote about the meaning of data already collected, and encouraging consumers of the news article to complete it.

Within articles by McKelvie, Drewett, Wooton and Murphy (2015), discursive objects were unclear, due to the breadth of topics and discourses drawn upon in them. From reading the headline of Murphy (2015), the impact of the wind turbines on autistic children would be the discursive object. However, upon reading the article, it was highlighted that the article delved deeper into the conceptualisation of autism, and the impact that had on day-to-day life, with the wind turbines being used as an example. As a result, explicit and implicit references to the discursive objects were difficult to conclusively identify. Overall, the article includes explicit references to both objects, with implicit references being used to describe the impact of sensory issues, with the windfarm being used as one example.

A similar pattern was identified in McKelvie’s (2015) article, with an initial discursive object of Aimee’s hen being identified, predominantly influenced by the

headline, before considering the effect of her autism diagnosis more broadly. Explicit references were identified through descriptions of the chickens, however, implicit references focused upon the role of these chickens in Aimee and her family's life, and her experiences of autism. Whilst the article was relatively short (321 words) and did not allow for a clear main discursive object to be identified, there was no certainty that further narrative would ensure this to be clarified.

From reading its title and headline, Drewett's (2015) article would appear to view the action of removing a mum's autistic daughter off a plane, to be the discursive object. However, upon reading the article further, the chronological narrative account of the events which led up to this action, were added to by a complaint discourse, drawing attention to the reason why her daughter was "*forced off plane*". Explicit references to the action featured 5 times, with these featuring in 3 successive sentences in the introductory paragraph. Implicit references to the action were not identified, however, this was expected due to the discursive object being a single act which occurred once. Regarding the additional discursive object, the reason why the individual was removed from the plane, several explicit references were made postulating why this happened. In addition, implicit references featured, using a quote from the airline, given in response to the complaint.

Wooton (2015) was unique in its inclusion to this discourse analysis, as the content referencing female experiences of autism featured following an alternative narrative about the subject's medical experiences. The article functions as a commentary following an interview between the author and a well known personality provides a context to the shift in topic. For this discourse analysis, the portion of the article focused upon the subject's medical was not included. Within the included text, a discursive object of an autism diagnosis was identified, as well as a discursive object of the impact of receiving that diagnosis. Whilst identified individually, there was overlap between these two objects, mainly as they were used within the same personal narrative. Explicit references were featured prominently when describing the experiences and challenges faced, with implicit references featuring in direct quotes included. For example, the description of how a diagnosis has meant being able to "*map out how this thing progresses*" (the thing being autism).



### 5.3.1.2 Stage 2: Discourses

As shown in table 18, several discourses were identified across multiple articles. As articles are identified through a numerical code, the discourses were coded using letters to avoid confusion. Many of the discourses in table 18 have been outlined in previous literature, however, their use in each of these articles requires an understanding of their influence on action orientation and positionings (stages 3 and 4 of analysis). Interestingly, all coded discourses were identified in at least 4 articles, with the discourse of autism causing difficulties, being the most frequently highlighted (within 7 articles). Drewett (2015), Murphy (2015) and Gask (2015) drew upon 7 individual constructs, 3 of which featured in all articles (adolescence, anti-medical model, and autism community). Whilst the medical model of disability, as defined within the literature along with widely cited descriptions of the deficits or challenges faced due to diagnosis, may further increase its prevalence, due to links between the medical and deficit models.

Discourses drawn upon	Code	Topic	Articles
Medical model of disability	A	Need for a diagnosis	2, 6, 8, 9, 11
Disability affecting home life	B	Child's disability affects others	2, 3, 8, 10
Ability / Disability	C	Ideas of difference, conceptualization of being 'special'.	2, 5, 7, 8, 9, 11
Adolescence	D	Challenges in teenage years	1, 3, 5, 6
Attainment / academia	E	Disability and influence on education	1, 6, 7, 8, 9
Blame culture	F	Link between diagnosis and negative consequence Complaint	1, 3, 5, 8, 11
Anti-medical model	G	Social views of disability and inclusion	3, 4, 5, 6, 7
Autism community	H	Prioritising things that matter to Autistic people	3, 4, 5, 6, 7

Person centred support	I	Real life and challenges faced	3, 4, 6, 7, 10
Autism causing difficulties	J	Social communication	1, 2, 3, 5, 8, 9, 10
Diversity	K	Importance of diversity, limits to diversity	4, 5, 6, 7, 9, 11

*Table 18: A summary of the discourses identified in articles.*

### *Medical model of disability*

The medical model of disability was viewed as a discourse as it identified in academic literature and has key characteristics (for an in-depth discussion see literature review). Within this, the need for a diagnosis was identified, as well that in the article's individuals all had a diagnosis.

There are interrelated links between the discourses included in table 18. For example, the diversity discourse is not exclusively positive. A specific example is article 11 (Ne'eman, 2015), in which the discursive object of screening sperm donors for autism, actively promotes limiting diversity, reinforcing views of autism affecting others, attainment and prospects (Disability affecting home life, ability/disability, attainment/academia, autism causing difficulties and diversity). With diversity (code K) been identified in several articles, it is worth noting that similarly to identifying explicit and implicit references to the discursive object, in stage 1, the identification of wider discourses also encompasses both types of reference.

### **5.3.1.3 Stage 3: Action orientation**

The constructions used within article 2 (Willis, 2015) focus on the benefit and positive impact of the specialist school for Charlie. This was reinforced by the narration provided by the author “...*Charlie moved to a specialist school in Frome, Somerset, for children with autism and became a different, happier girl*”. The portrayal of the transition from a girl ‘*trying to slash her wrists*’ to ‘*a beauty queen*’ presents a positive outcome for readers, as well as drawing upon the extreme sides to the story. It is worth noting that Charlie did not contribute to the article, and therefore, the narrative was shaped by others, namely her parents. Drawing upon the discourse of autistic people being a strain on their family, as well as the role of receiving a diagnosis, the

article utilises several quotes from Charlie's mother, *"I was relieved that we had a diagnosis..."*, *"I didn't know what to do to help"*.

Similarly, article 1 (Tozer, 2015) focused upon the role of diagnosis and the impact of Elspeth's behaviour on her family. Whilst the context of the article was different, as it was based around the inquest into her death by suicide, descriptions of the effect on others featured heavily *"we got woken up in the middle of the night... there were behavioural issues..."*. Interestingly, this article's title leads us to assume that there was a direct causal relationship between receiving a diagnosis and death by suicide. However, whilst quotes support that Elspeth *"did not want the diagnosis..."*, there are indicators that this was not the only cause *"she did feel an awful lot of pressure..."*. Several references are made to her attainment, by the description of her being a *"school prefect"* and an *"A\* student"*, which may present several possible functions; to demonstrate that attainment does not negate difficulties, and to challenge assumptions that autism is linked with intelligence.

Within article 4, Kurchak (2015), who identifies as autistic, uses discourse to put forward their own views and experiences. Though it is also clear that they believe their views to be that of a wider community. The purpose of drawing on medical discourses, including the role of diagnosis, may be intentional due to its frequency in literature. However, this article challenges what society should be focusing on, for example, what should awareness focus on, and is a cure desirable? The use of language such as *"if you..."* and *"our needs"*, not only draw the reader to feel involved, but also assert these views are much wider in the community. Ensuring personal experiences and circumstances are viewed to be the most important consideration, with the discourse outlining the need to reflect real experiences in campaigns or projects that aim to increase awareness.

Like Willis (2015) and Tozer (2015), article 10 (McKelvie, 2015) focuses upon a narrative in which the discursive object, in this case Aimee's pet, is portrayed as the cause of a positive outcome. From reading the title it would imply that this would be the focus of the article, however, there were alternative discourses drawn upon. These included the impact of diagnosis and getting a pet on her family, including the *"dilemma when Aimee begged for a pet"*, and how the *"garden has been*

*completely taken over.... we have the added bonus of eggs for breakfast*". As Aimee does not comment within the article, we are unable to understand her views and experiences of getting a pet. This resonates with discourses of individuals having a voice, being viewed as equal and as agents of their own lives. The article's portrayal of the decision to get chickens implies it was based on her parent's views and possible disruption to their lives, rather than Aimee's autonomy in voicing her needs. The discourse throughout the main body of the article does not fulfil the discourse identified when reading the title, though the reasons for this are unclear.

Drewett (2015) in article 5 uses a family's experience of being *"forced off a plane"*, to present several discourses, encouraging readers to have an opinion on the discursive object. The use of language such as *"slammed"*, and *"prejudice"* have likely to been used to intensify the feeling of wrongdoing for the action taken, as well as being terms that generate an emotional response. However, whilst the explanations given for the *"disruption"* caused highlight some of the sensory challenges associated with autism, a discourse of entitlement and causation can also be identified. The discourses drawn upon demonstrate a simplified view that autism causes sensory difficulties, which is why she had a meltdown, which then resulted in the flight diversion, and views of discrimination being voiced. The authors' reliance on direct quotes throughout the article further supports the function of allowing readers to make their own opinions and reactions to the experiences described.

Article 8 (Wootton, 2015) draws upon quotes and a narrative directed by a well-known controversial public figure. The impact of the article on lay readers is likely to be influenced by the controversy associated with her, and thus, the functions of the discursive object and discourse may challenge negative perceptions of the public figure. Nonetheless, analysis solely based on the discourse provides us with an insight into the perceptions of autism by that individual, as well as the impact on her family. Frequent language used highlights views linked with a deficit-model and autism being viewed as something *"wrong"*. In addition, implicit meaning went a long way to highlight her beliefs about autism. Quoting *"people assumed I had these perfect children..."* implies that due to her daughter's diagnosis she is not *"perfect"*. The impact of her daughter's diagnosis is viewed through descriptions of her reliance on others

and the impact it will have on the family's life, as she is *"likely to live at home for her entire life"*.

Ne'eman (2015, article 11) presents a controversial topic in which the author, who identifies as autistic, challenges the discursive object of screening sperm donors for autism, whilst drawing upon wider discourses of choice, and the importance of diversity. Descriptions of *"turning away autistic donors"* reinforces views of undesirability, whilst also presenting questions as to how far this will go. The social model of disability is inherent throughout the article, specifically when describing *"disability has always been contextual"*. The discourse provided by the author is in clear opposition to the screening processes, drawing upon questions as to how far it would go in descriptions of *"designer children"*. An interesting feature within this article is that consideration of autism in females received a considerable amount of attention. It was included through discussions of the possible influence of the diagnostic disparities between males and females, with this in turn affecting the screening process without disclosures of diagnoses in the family.

Article 7 (Neustatter, 2015) utilises discourse to present a transformative narrative, in which the school is the catalyst. In addition, views of autism resulting in challenges to society are reinforced when describing a school's inability to *"cope with her"*. Wider considerations of the diagnosis of females with autism is provided through a comprehensive discussion around the topic, including quotes from experts. Perhaps the most interesting discourse features towards the end of the article, when describing how the school *"takes any girl they feel they can help (the local authority usually pays if the girl is statement)"*. Whilst the use of the words *"takes any girl"* implies an inclusive environment, the subsequent inclusion of a comment about financing the education may reinforce the discourse of autistic individuals being burden and drain of resources. The purpose of including a statement about funding the education is unknown, though it may draw upon discourses that explore views of responsibility in financing education which is able to meet an individual's needs.

Article 9 (By Telegraph Men, 2015) presents a discourse of science as a gold standard for knowledge and reliability. Furthermore, the language of how the study has *"confirmed that men are more likely to be autistic than women"* goes to reinforce

the certainty and credibility of the information. The descriptions of “*genetic mutations*” when describing the symptomology of autism goes to reinforce a medical model of finding a fault, and further, reinforcing a deficit driven view of disability and difference. The overly simplistic view of autism has several potential consequences, including individuals believing they have autism if scoring above the threshold on the test. In addition, should someone who has already received a diagnosis takes the test and score under the threshold, it may challenge their autonomy and agency. The use of medical jargon throughout the article goes further to reinforce the view of disability as something that is quantifiable and measurable. In addition, the complexity of the topic may therefore be viewed as something out of the realms of a lay readers and something that does not concern them.

Murphy (2015) in article 3 uses a personal narrative in a similar way to Drewett (2015), with a likely outcome for a reader being forming a position in which an opinion may arise. Whilst the article goes some way to explore the daily experiences for autistic people, the second-hand interpretation reinforces the discourse of autism affecting an individual’s support network and those around them. Descriptions of how the wind turbines would affect her children’s health, along with frequent citing of “*symptoms*” and “*diagnosis*”, assimilate a medical model of disability. Again, similarly to article 5, the concluding section focuses upon discourse provided by someone detached from the narrative, with their authority and position being provided. The first identifies the risks and challenges faced by those “*with sensitivity to low-frequency vibration*”, whilst the second contests that research does not “*show any direct health effects of wind turbines*”. Again, research is drawn upon, suggesting that this is a gold standard, and epistemological positions that what we know comes from research. The use of two opposing positions may reinforce the outcome of the reader forming an opinion that aligns on the spectrum encompassing the cited quotes,

Article 6 (Gask, 2015) provides a platform for personal narratives and experiences to be shared in supporting the context of the book being promoted. Discourses of the role of achievement do feature when providing a context to the book’s creation, however the overall focus is upon the personal benefits of co-producing and participating in writing a book. The language surrounding autism is complex, with varying opinions and preferences as to how one identifies. This article is unique in which it does not

conform with the person-first language used within the other articles. It is hoped that this is due to this language being the girls' preference, rather than the authors. The citing of co-production may be viewed as evidence to support this assumption. Capturing "*the highs and lows*" of the girls included in the book, discourses of difficulties as well as ability feature. This can be seen to demonstrate the importance of a holistic view of an individual, as well as challenging the deficit driven medical model. The girls' ability to participate and voice their experiences draws upon agency discourse, and views that children should be able to share their opinions in matters that concern them (UNCRC). Overall, the constructions utilised in this article aim to present the authentic voices of girls with autism, whilst also including "*evidence*" and "*research*", which is assumed to be included to validate the experiences shared.

#### **5.3.1.4 Stage 4: Positionings**

This stage of analysis focused upon the subject positions which are made available within the articles. Subject positions focus upon wider discourses, presenting a view or opinion of them. For example, in article 2 (Willis, 2015), the discourse of recovery and positive outcomes after experiencing adversity, is enhanced, and supported through the narrative. Explicit references to this were provided, "*...a complete transformation from the terrified and depressed girl...*". In comparison, Tozer (2015, article 1) positions receiving a diagnosis of autism as being the catalyst for a girl to die by suicide. Positionings surrounding tragedy were tackled within article 4 (Kurchak, 2015), through the first-hand exploration of the perceptions of autism and false understandings portrayed in awareness training. Interestingly, this positioning described the possible impact of "*genuine awareness*" being able to "*greatly improve the lives of people both on and off the spectrum*". This statement subsequently draws upon perceptions that autistic people can be a burden or challenge to wider society. Again, in Kurchack (2015), the narrative ascribes to the idea of recovery, through descriptions of how the discursive object, Aimee's hen, being central in helping to "*bring the 11-year-old out of her shell*". Wootton (2015) in article 8 positions autism as a limiting factor of one's ability to be independent, as the narration, provided by a parent, describes her belief that they "*think she'll (daughter) live with us forever*". This also positions autism as requiring support from others and relying on them to function throughout their lives. A position in response to views

of recovery and development did not explicitly feature in Ne'eman (2015, article 11), however the view of autism being undesirable, and needing to be eliminated, goes to reinforce the negative perception of autism. Whilst articles by Neusttater (2015, article 7) and Gask (2015, article 6) presented a narrative including a more positive conclusion, the focus was not on the act of recovery, rather, the strategies and support put in place which facilitated the better outcomes described. Murphy (2015, article 3) enlists the discursive object of the building of a wind farm to exemplify the possible negative outcomes for the individuals described within the narrative. As such, focuses upon the external factors which influence the functioning and ability of autistic individuals to go about their daily lives.

The preference and success of specialist provisions for autistic girls was cited across several articles. Within Willis (2015, article 2), the change in Charlie's presentation was ascribed to the beneficial effects of being within a specialist school "*...within weeks (of the move) she was jumping out of bed to get to school*". Article 7 (Neustater, 2015) also acknowledges the role of specialist provisions, though it is cited to coming after a mainstream school "*could no longer cope*". The role of specialist provision was cited within Murphy's (2015) article (3), as being positioned as being a place of safety, enlisting first-hand accounts of individuals' experiences of mainstream school to reinforce benefits of specialist provision "*the anxiety I felt all day at mainstream school used to make me vomit...*".

Whilst the identification of diagnosis as a discourse featured in the previous stage of analysis, this stage identifies the varying positions of receiving a diagnosis for the individuals featured within the articles. In article 2 (Willis, 2015), parental accounts identified feeling "*relieved*" for their daughter to have a diagnosis, they also acknowledge it as being an indication that their "*future was going to be very different*". Tozer (2015, article 1) is perhaps the most complex in its positioning of diagnosis, due to the causal link between that and death by suicide cited in its title. However, whilst the diagnosis was cited as not being wanted, the reasons for this were not necessarily linked with it explicitly. Descriptions were given about negative views of the mental health team being "*toxic, and more about her mother's needs*", as well as how Elspeth "*was happy to be odd an eccentric*". Kurchak (2015, article 4) presents diagnosis as a time in the authors life which "*was an explanation for all of my sensory*



*sensitivities, social issues, repetitive behaviours and obsessive interests*". Drewett (2015, article 5) enlisted an autism diagnosis as an explanation for the requirement for specific adjustments to be made, whilst also reinforcing the discourse of complaint to be due to *"prejudice, ignorance and mistreatment"*. Similarly, Murphy (2015, article 3) describes the impact of autism on daily life, as well as reinforcing the difficulties posed should the wind turbines be erected. Within article 8 (Wooton, 2015), the diagnosis of autism explained the challenges faced in early childhood, whilst also reinforcing the predictions of the future outcomes for the individual. Article 11 (Ne'eman, 2015), which may be viewed as the most controversial, positioned diagnosis as a reason that some donors could get turned away, whether that be an individual themselves, or within their family history. Whilst not explicitly cited, diagnosis is positioned by Neustatter (2015, article 7) and Gask (2015, article 6) as more challenging in females, with estimates given that there are *"five times as many males to females with autism"*.

#### **5.3.1.5 Stages 5 and 6: Practice and subjectivity**

Various possibilities for action were identified in each article, as well as what could be said and done from the way in which subjects were positioned. Within Willis' article (2015, 2), the positive influence of diagnosis and prescribed medication may push people to seek this if they are in similar situations. In addition, this may be interpreted as a treatment for the difficulties faced, and encourage parents, or individuals, to seek such intervention so that their difficulties can be resolved.

Tozer (2015, article 1) included several key possibilities for action that could result from reading the article. Firstly, the negative outcome for Elspeth may go one of two ways, either to reinforce negative views of autism, or encourage the role and views of diagnosis to support an understanding of an individual's presentation. The reference throughout the article to academic ability, challenges perceptions that autistic individuals have low levels of intelligence, but also that a seemingly high intelligence and functioning does not negate or counteract challenges.

Through article 4's (Kurchak, 2015) clear narration, possibilities for action are explicitly stated. The importance of person first and individualised support is clear, as well as challenging the medical model and the desire to cure autism. This article

presents a clear stance and enlists evidence to support this, with linguistic choices implying the view is that of a wider community. The articles clear message may attract support from others represented in the community, as well as challenging the beliefs that readers may have about the topics discussed. It is also possible for people to read the article in agreement with the practice of screening taking place.

Like Tozer (2015, article 1), the discourses drawn upon in McKelvie (2015, article 10) could be interpreted across a spectrum between two extremes. Descriptions of the challenges faced may result in assumptions that a diagnosis of autism means that you are not wanting and unable to maintain friendships. On the other hand, it may be viewed as a forward-thinking method that improves the well-being of an individual.

Due to the clear dissatisfaction felt by the parent described in article 5 (Drewett, 2015), it is likely that this would elicit strong views from readers. The positioning of autism as an explanation for the behaviour may be seen by some as making an excuse, and an expectation that any needs should be met without challenge, or people may relate to the challenge and consider it to be a reasonable adjustment. The negative consequence of being removed from the plane may go to reinforce the stigma associated with receiving a diagnosis, or may resonate with readers as something they have experienced or witnessed. Several questions may present by readers, including what the family experienced on the prior journey (as they were returning from a holiday), and why they did not know that hot food was not provided (the article states that only first-class passengers could have hot food). Similarly, Murphy (2015, article 3) presents a topic which is likely to elicit an opinion being formed by the reader. The comparison of varying expert accounts of the impact these wind turbines may have go further to reinforce the topic as contentious and one which is subject to debate.

Article 8's (Wooton, 2015) well-known media personality will no doubt influence the possibilities for action after reading the article. Though, drawing away from this, her own narrative of the role of autism in her daughter's life may go to reinforce the deficit driven model and perceptions of reliance that feature within society. On the other hand, the descriptions of the day-to-day experiences of having an autistic child may be relatable for readers, and challenge perceptions that diagnosis is sought due to receiving benefits that otherwise would not be available.

Ne’eman (2015, article 11) presents several implications, namely focusing around reinforcing the stereotypes of autism being undesirable, should readers agree with the discursive object. As the narrative challenges the action, individuals may question the practices that take place and as such, may prompt action.

Neustatter (2015, article 7) and Gask (2015, article 6) both present possibilities for action following the consumption of their content. Their purpose of challenging stereotypes may evoke others to do the same, as well as questions as to why these provisions are so scarce. However, due to both articles drawing upon the creation of a documentary and book, we should acknowledge the role of the articles as being to encourage readers to consume these.

The clear possibility for action within article 9 (By Telegraph Men, 2015) is for readers to take the test. The positioning of the quiz amongst a wider “*experiment*” only goes to encourage readers to add to the data already gathered. The descriptions of previous findings may also encourage individuals to complete the questionnaire for them to compare themselves against the “*threshold to indicate a likelihood*” (of autism). Lexical choices such as “*take the test to help...*” further encourage readers to complete the quiz. Whilst the purpose of a discourse analysis is to draw upon the news articles themselves, this article’s clear purpose provides an explanation for the strategies employed and discourses drawn upon.

Stage 6 focuses upon the potential thoughts experiences by readers when consuming the news articles. Throughout all the articles, these experiences also include questions that the discourses may guide readers too. Within Willis (2015, article 2), the journey from a negative situation to a more positive one may reinforce views of it being possible for other people too. Whilst this is positive, the lack of personal quotes and opinions for the individual being described, readers may want to find out more, and question who the benefits are for, is it the individual or her parents and those around her? Article 1 (Tozer, 2015) primarily encourages an evaluation of the role of autism diagnoses, and for whom these are beneficial or useful for. The tragic outcome is undoubtedly going to elicit empathy from a large proportion of readers; however, stigma of death by suicide is worthy of consideration. As the writer’s position in article

4 (Kurchak, 2015) is of someone within the community being described, it is likely to influence the discourses used and the way in which the narrative is presented. In addition, it may encourage self-reflection of one's own beliefs surrounding inclusion and ensuring people's real-life experiences are the focus in awareness campaigns.

Within McKelvie (2015, article 10), feeling may include that of the influence of autism on the wider family, with the hen in this case being used to demonstrate this. Also, the portrayal of how a hen changed the outlook for the individual is a positive, though the narrative being shared through the parents' perspective may reinforce the views of children as being dependent on adults and vulnerable. Article 5 (Drewett, 2015) presents a few possibilities that could be taken by readers, namely views they could take. These include views that people with disabilities complain and are expectant that their needs are met and was there something that was not included in the article which would further explain the decision to remove the family from the flight.

### 5.3.2 Findings: Analysis (2019)

#### 5.3.2.1 Stage 1: discursive constructions

Article	Discursive object
1 – Gill	Bullying
2 – No author	Girls and Autism Project (GAP)
3 – O'Boyle	Autism in girls
4 – Birrell	Greta Thunberg
5 – Hill	Autistic teenage girls
6 – Nolan	Autistic females' diagnosis
7 – Worth	Process of diagnosis for autistic females
8 – Leake	Autism diagnosis
9 – Silverman	Advocacy and speaking up for a cause
10 – Jones	Positioning autistic people in society
11 – Leslie	Representation of autistic people on television

*Table 19: Discursive objects within included articles.*

Within article 1 (Gill, 2019), a discursive object of bullying was identified. Explicit references focused upon the actions that occurred, with implicit references that position autism as a reason and catalyst to the events that are described. Through highlighting these references, it emerged that implicit references were generally identified in supporting quotes within the article, and the explicit references being embedded in the narrative provided by the author.

Within article 2 (NO AUTHOR, 2019), the discursive object was the Girls and Autism Project (GAP). Explicit references focused upon the project and a description of its purpose, with implicit references focusing upon the role of the project in facilitating positive outcomes, such as positioning it as a causal reason for the individual 'flourishing'.

Article 3 (O'Boyle, 2019) presented a discursive object of autism in girls. It is constructed as an area that is needing to be explained, framed through the explicit references to the discursive object, with implied references through narratives of assumptions and stereotypes experiences in males. The discursive object enlists language such as 'they' and 'girls with the condition', which assisted in identifying the discursive object within this article.

In Birrell's (2019, article 4) article, the discursive object was identified to be an individual, Greta Thunberg. This discursive object draws upon the global prevalence and popularity of Greta to open discussion about autism. Explicit references are more frequent in the first half of the article, with implicit references appearing in the remainder. Implicit references were utilised when describing others' experiences, as well implications that she has brought forward these discussions to the public domain.

Identifying the discursive object in article 5 (Hill, 2019) was not as clear as other articles, namely because of the focus within the article of a book that is being promoted as an additional consideration that the discursive strategies being employed. Explicit references to the discursive object, autistic teenage girls, can be identified within the

author's narrative as well as quotes provided. Implicit references provide thoughts of why this group may present differently, as well as wider concepts of adolescence.

Article 6 (Nolan, 2019) presents a discursive object of autistic females' diagnosis. Possibilities for the increase in diagnoses is discussed, with the discursive object positioned as a factor. Implicit references were included through discussions of 'female presentation'. There are a majority implicit references in this article, with the explicit references featuring in the opening sentence and quotes provided within the narrative.

Within Article 7 (Worth, 2019), the discursive object was identified as the process of diagnosis for autistic girls. This was conceptualised through themes of the different presentations when comparing to males, going on to suggest reasons this may be. A balanced amount of explicit and implicit references were cited within this article, with implicit references often focusing upon the reasons why diagnosis for this group can be challenging, in addition to descriptions of research findings.

Whilst initial thoughts viewed the failure 'to spot autism' as the discursive object, upon reading the full article (8, Leake, 2019), a discursive object of the diagnosis of autism was confirmed. This included explicit references to receiving a diagnosis and the impact of receiving a diagnosis. Implicit references included discussions as to why diagnosis in females is on the research agenda, as well as reinforcing the position of research in wider understandings within society.

Article 9 (Silverman, 2019) presents a narrative as told to them, directly quoted from another source (Carly Jones, MBE). The discursive object was identified as advocacy and speaking up for a cause. Explicit references were more frequent within the article, with implicit references drawing upon others who have roles in advocacy, namely Greta Thunberg.

In comparison to previously identified discursive objects that are static, article 10 (Jones, 2019) presents the reader a conceptual object of positioning autistic people in

society. This object utilises personal experiences and high-profile (such as Greta Thunberg) links to describe society as underpinning misinformation, in turn discussing the impact of this on autistic people. Throughout the article, explicit and implicit references appear balanced, though it is interesting to note that the first reference to this object identified in the article is implicit. This is followed by an explicit statement referring to the object: *‘there are two mainstream narratives surrounding autism: that it is either a blessing or a curse’*.

The discursive object identified in article 11 (Leslie, 2019) is the representation of autism on television. Explicit references focus upon giving the reader examples of autistic characters, utilising these to provide a structure, with implicit references following these throughout the paragraphs.

### 5.3.2.2 Stage 2: discourses

Wider discourse	Articles
Social model of disability	2, 4, 5, 7, 9, 10, 11
Medical model of disability	2, 3, 4, 6, 8
‘Superhero’ discourse	4, 11
Role of diagnosis	2, 3, 5, 6, 7, 8
Autistic presentation	3, 4, 5, 7, 10, 11
Gender disparities	3, 5, 7, 8
Self-advocacy / narratives	1, 4, 5, 9, 10, 11
Vulnerability	1, 4, 9
Technology / Media	1, 10, 11
Language surrounding diagnosis	1, 2, 3, 4, 5
Expertise	6, 7, 8, 11

Table 20: A list of wider discourses and articles they were identified in.

Article 1 (Gill, 2019) draws upon the discourse of vulnerability, in that the cause of the bullying was because of the autistic characteristics *‘...resulting in them using this as a*

*target to bully....*'. Further, the discourse surrounding self-advocacy was identified in that the narrative was provided by the girl's mother, which may serve to reinforce the vulnerability and victimisation concepts. Though, midway through the article, embedded in a quote from the mother is a statement identified as being recalled to her from her daughter *'mum there's a video of me getting beaten up on Snapchat'*. When considering the positioning of the autistic girl this article focused on, it is worth noting that she was the third 'voice' in the narrative, as the author and mother all presented their accounts. The changing dynamics of communications in adolescence are embedded within this article as discussions about online recordings of the bullying demonstrate. Positioning disability in this article, language preferences in the title present identity first language *'...autistic schoolgirl...*', whereas in the opening sentence this differs when referring to who was subject to the bullying *'a schoolgirl with autism'*.

Article 2 (No author, 2019) draws upon models of disability when describing the family's *'respite'* in the title, as well as in a quote from her mother. In both the title and the quote, this follows a positive statement about Chelsea, *'teenager is flourishing'* and *'the best bit of it is that she's meeting other girls going through similar things...'*. This draws upon assumptions of a reliance on social support and intervention. Another discourse is surrounding the role of diagnosis in accessing support. Specifically, a quote identifies the perception of being *'lucky because we got a diagnosis...she was just five...'*. Again, this article utilises quotes to contribute to the narrative, mainly from her mother, and at the end, from a teacher at her school. These focus upon positive implication of this project on her social skills and contributing to supporting other autistic children. In comparison to Chelsea's mum's quotes that utilise identity first language (*'autistic child'*), the author later use *'children with autism'*, which aligns with a medical model.

Article 3 (O'Boyle, 2019) draws upon a range of discourses which align with research developments and understandings. In addition, in the introductory sentence, a medical standpoint is established; *'it's a condition associated most strongly with men and boys'*. This continues through the article when referring to *'girls with the condition'*. The



article acknowledges the imbalance in diagnoses in males compared to females, presenting opinion about the reason for this. Contextually, this piece was published around World Autism Awareness Day, so may have had more attention paid to the language and discursive choices made. The use of '*special needs*' when describing a project, the connotation to many would be negative as it can be linked with positioning an individual outside the 'norm'. Though, the article then goes on to show an appreciation for these differences. Discourses surrounding the presentation of autistic females is discussed, including examples being provided by the positioned 'expert', working on the project being discussed.

Birrell (2019, article 4) utilises a known autistic individual, Greta Thunberg, to open discussions and wider discourse. Specifically, the medical model is presented through language choices, with autism being referred to as a '*condition*'. Further to do this, describing Greta as a '*global icon*' draws on a superhero discourse, whilst also reinforce this being more impressive being '*just 16 years old*'. This is reconsidered later in the article through descriptions of other autistic people and their achievements, and the role of '*harnessing difference for wider societal benefit*'. Birrell describes accounts from families of '*girls with autism like Thunberg*' who had different experiences, including descriptions of the psychiatric units where they were placed in 'solitary confinement'. Recalling on these experiences in the concluding paragraph positions this as '*costly*' first, may reinforce the perception of autistic people being a burden. Overall, on an explicit level this article makes language choices that appear to acknowledge the unique barriers and experiences autistic females face, though language choices and some of the wider discourses reference go against this.

In article 5's (Hill, 2019) title misdiagnosis is cited as an issue, with a solution to this being provided in the description of the '*graphic novel*'. Discourses surrounding the role of research and knowledge is included, with an including quote describing how '*there's loads of autistic research on women, but it's written exclusively, for research communities*'. In addition to a quote from a researcher and the book author, further quotes from autistic teenagers are included, drawing on the discourse of autonomy and challenging ideas of autistic people being too vulnerable to be included in articles.

In the authors narrative provided, '*experts*' are positioned as the ones to be trusted, potentially due to the validity associated with their positions and qualifications. The wider discourse of the role of a diagnosis and the need to receive one is discussed through the statistics providing surrounding the diagnoses in males and females, and at what age these were received. Again, quotes from autistic females are used to describe their experiences around gaining a diagnosis. In the concluding paragraph the social model is embedded as the book author's preference, describing that '*society has to change, not autistic people*'.

Nolan (2019, article 6) positions an improvement of autism diagnosis in females as why '*autism rate hits a high*'. The introductory two paragraphs utilise medicalised jargon and linguistic choices to address this, including how '*increased recognition of girls with autism is one reason why diagnosis rates for the disorder reached the highest level on record...*'. It is not clear the authors position of whether this is a positive. These also featured in accounts provided by perceived experts. Utilising contributions from other sources to the article may suggest that there is a level of expertise required to discuss the topic. This was explicitly stated when describing Professor Louise Gallagher as '*a leading expert on autism...*'. In comparison to previous articles, diagnostic rates are framed as specialist, rather than being a matter which should be a wider societal concern.

Within article 7 (Worth, 2019) subtitles are used to present the article, as well as a 'highlight' sentence at the start to provide a summary. This, alongside the title present the topic area as something that can be actioned by various stakeholders, such as teachers. Receiving a diagnosis is aligned with supporting autistic girls, but issues of 'missing the signs' can hinder this. In asking '*why do we need to put a label on these girls?*', the author acknowledges some of the wider questions and discourses around the medicalised processes of diagnosis. The response provided by the 'expert' positioned first the importance for an individual's identity, before describing it resulting in the support '*that will benefit them for the rest of their life*'. Interestingly, when describing the ability to mask difficulties, positive language such as 'ability', 'learn' and 'get around the problem' is used, which aligns with the social model of disability, rather

than framing these to highlight a deficit. Direct quotes are used to provide examples of camouflaging from a perceived 'expert', though these draw upon comments made from autistic people and their families.

By including such a short strong title in article 8 (Leake, 2019), discourses that focus on blame can be identified. Positioning the experiences as '*symptoms*' acts to align with the medical model, linking back to positioning '*doctors*' as those to blame. Again, the role of research is valued through this article, with gaps in such research framed as the reason for the issue; '*it has created a view that girls don't get autism- so doctors don't see it and diagnose something else*'. Enlisting a second 'expert', the challenge and '*fight to get diagnosed*' is discussed, with the effect of this also being included. Later in the article, medical lexis is used in describing how '*the condition (autism) affects about 700,000 Britons*'. When listing the consequences of not receiving an appropriate diagnosis, positioning 'academic chances' before considered going without support may indicate the authors views of what is import.

In comparison to the other included articles, article 9 (Silverman, 2019) is entirely constructed of direct quotes, with a line at the end informing the reader that the context was '*as told to Rosa Silverman*'. When considering wider discourses, the complexity and controversial nature of the topic may explain this, as by doing this it may relinquish any adverse responses to the publication. Alternatively, it could be as the quotes were considered appropriate to get the meaning across, positioning the expert as the person who experienced the topic. In framing autism, positive descriptions of it bringing a 'gift' as well as acknowledging that there are '*challenges and vulnerabilities too*'. By including a reference to Greta Thunberg being '*mocked...on Twitter*', it involves wider discourses of some of the negative experiences that can occur.

Article 10 (Jones, 2019) is underpinned by the social model of disability. The presentation of autistic characters in the media is positioned at the centre of this article, describing how '*depictions of autism frequently fail those they claim to represent*'. Explicitly acknowledging the narratives that surround autism as a '*dichotomy*' in that

autism can include '*savant-like traits and excel in...mathematics*' or as '*the reason you are isolated alone and miserable*'. Utilising linguistic choices of 'we' when describing these topics draws on the discourse of an autism community, as well as positioning the depictions in media as what '*neurotypical people think autism is*'. Through the authors self-declaration of being autistic, a description of self-discovery and finding the '*thriving community*' is presented. Overall, the article presents the importance of engaging with the autistic people as their experiences may be different than others' interpretation and representations of them.

Leslie (article 11) clearly outlines their own diagnosis when describing the dismissal of difficulties and being categorised as '*different*'. Drawing on the role of autism as an understanding of one's identity, this article presents this in ensuring that '*identity is reflected properly on screen*'. When describing examples of television and films that included autistic representation, the author focused upon the creation of these characters and those considered 'experts' in developing these. It was clear how utilising 'involvement from the autism community' is synchronous of a move in the '*right direction*'. With the specific focus upon media, the role of characters that represent true autistic identity mean '*perceptions can change*'.

### **5.3.2.3 Stage 3: action orientation**

Gill (2019) presents a narrative of a bullying incident, which may reinforce the stereotype of vulnerability.

Interpretations of article 2 may centre on the term '*respite*'. This positions autism as something of a burden to family and thus needing of this respite. Further, connotations of the positive outcomes after receiving a diagnosis may reinforce the focus and push for a diagnosis.

When presenting the findings of academic research, O'Boyle (2019) utilises user friendly language to present the key arguments. Specifically, this may encourage the reader to be considerate of different and understanding the individuality of autism experiences. Deploying the object of female specific experiences aims to increase

understanding of this topic, which may align with the context of being written to '*mark autism awareness day*'.

Positioning Greta Thunberg in Birrell's (2019) article automatically brings possibilities for action as she is a well-known figure. The language use in this article, that goes against the community's preference, may encourage readers to internalise this and use this in their lives. Descriptions included provide extreme and stark examples of difficulties, which are likely done to induce an emotional response to the article.

Article 5 positions society as needing to change to become more accepting, recognising the real-life experiences of autistic females. Utilising personal quotes from autistic people may encourage the reader to relate to the topic. As the article is focused on a new novel, it is likely that the purpose of this therefore was to encourage readers to buy and read the book.

As Nolan (2019) presents elements from the medical and social models of disability, it provides the reader with the two ends of a spectrum encouraging them to align with one of them. Constructing diagnosis alongside statistics and numerical data positions diagnosis in a simplistic manner. Framing in the title presents an assumed positive that diagnosis rates have 'improved', though, if readers align with views of autistic people being a burden, this may encourage a negative response.

Exploring the discursive object and discourses drawn upon by Worth (2019), it appears that academic information can be disseminated to a wider audience, challenging perceptions of it being something only 'experts' can be engaged. Through the positive orientation and framing through the article, it is likely to reinforce this to the reader. As the article is featuring in the educational supplement, the audience are more likely to have come across the topic area previously. The context of the article is important when considering the opportunities for action, as it is positioned in the title that there

is a role for the reader to play '*how to identify autistic girls – and what you can do to help*'.

Leake (2019) present an engaging title which implies an element of blame where doctors 'fail to spot autism'. However, opportunities for action may be limited for a consumer who does not align with the medical or academic profession. Presenting clear descriptions of an alternative presentation to what is often portrayed in the media, it may be with the purpose of increasing understanding. Introducing this topic in a news segment may encourage readers to find out more or to form an opinion.

In article 9, a personal account is provided which may encourage readers to form an opinion on the content, as there are no external quotes or thoughts provided in the article.

When Jones (2019) opens article 10, the applicability is reinforced through describing how '*autism has never been talked about more in the mainstream media*', which positions the topic as important for society, rather than presenting it as an issue of relevance to a certain group. As this article includes various discourses, such as the '*disability rights movement*', readers may seek to find out more about what this means. Using language such as '*absurd*', '*harmful*' and '*dire consequences*' clearly enables the reader to appreciate the authors views on the topic. These choices may also be persuasive in gaining the readers alliance to this view. Presenting the article in this way, with a clear link with mainstream subjects, such as television, is likely to highlight the issues to as many readers as possible, gaining momentum to the agenda of autistic people being the '*ones leading the conversation surrounding autism...*'.

Similarly, Leslie (2019) positions themselves within the article due to their own autistic identity. The role of the discursive objects and linguistic choices are likely to be selected as they can push forward the narrative of there being a '*problem*'. This topic is situated among a wider '*movement*' where autistic voices are viewed as experts, rather than those with a 'professional' involvement in the topic area.

#### 5.3.2.4 Stage 4: positionings

Article 1 (Gill, 2019) positions autism as the cause of the bullying experienced, whilst also conveying a narrative that readers would view as wrong. In addition, the events described as presented as expected and unsurprising, reinforcing discourses of autistic people being vulnerable to negative experiences. Including information about the school and how it '*requires improvement after its last full inspection...*' may infer that this was an influencing factor of the incident, potentially that the behaviours would not have happened if the school were rated more highly.

In comparison, article 2 (NA, 2019) positions the project as having a positive impact on an individual's self-esteem. Further, describing the positive effects upon friendships aligns with academic literature identifying this as an area of relevance in autistic teenage girls. The social world is acknowledged and positioned as being important, though differences between males and females are not cited.

O'Boyle (2019) adopts the position of autistic females requiring '*special*' provision, whilst also drawing upon terminology aligned with the medical model in the introduction. Embedded within the article features several quotes that shape the article, with these quotes implied as being 'expert'. Identifying a large portion of the discourse as the opinion or knowledge of others may create a distance between the author and the views expressed.

Greta Thunberg is positioned in article 4 (Birrell, 2019) as a major influence in driving change in awareness and acceptance of autism. Specifically, she is positioned as '*offering lessons on harnessing difference for wider societal benefit*'. The perceived superhero status of Greta contrasts with the narratives of autistic females experiencing adversity, implying a position that this group of people are likely to go one way or the other. Autism is positioned as a difference which can be used proactively so others may perceive it as a '*gift*', whilst also acknowledging the diversity of experiences autistic people face. The article positions society as needing to change and be more

accepting, whilst also utilising language that aligns with medical models of disability and not the autistic community's preference.

Hill (2019) positions the graphic novel as a way that the reader can access the object of autistic girls' experiences. By including excerpts and quotes from this within the article, it implies the author is aware of ensuring voices are heard and the experiences are accurately portrayed. Additionally, this article addresses the perception that this is a topic in research and available to academics, positioning it as something that is of importance in wider society and thus for the reader.

Positionings in article 6 (Nolan, 2019) depend on the way the reader interprets diagnoses hitting a high. Further, in discussing the widening of diagnostic criteria, an explanation for this increase is presented, as well as citing how '*the number of children undergoing evaluation...has increased sharply since the assessment of need process was made law in 2007*'. When positioning the reasons for the increased recognition, the author positions misdiagnosis differently to academic research, describing how there is '*no question of misdiagnosis...being a factor in the increased numbers*'.

Through Worth's (2019) article, the reader is given the opportunity for involvement, positioning the reader as an educational professional that has a level of knowledge about the topic. When describing the concept of masking, the author utilises positive language in describing it as an '*ability*' rather than aligning with language ascribed to deficit models. When reflecting on the positions enlisted in this article, these are likely to be influenced by the context of being published within the educational supplement and as such is modelled for this reader's demographic.

Through the title of article 8 (Leake, 2019), the position is set as needing to rectify the issue, failing to spot autism in girls. Using quotes from experts to support the narrative, the article positions these individuals as presenting truth and as such should be



trusted. Through the article, when postulating reasons for the issue, bias is positioned as an impact, specifically within medical fields and the training provided.

Silverman (2019) positions the autistic voice as prominent in the article through the discourse being direct quotes from Carly Jones. Drawing upon a widely known autistic person, Greta Thunberg, this article gives readers an understanding of others' achievements as well as providing opinion on the reasons why autistic people can do them. When describing autism, positives are described alongside the challenges and barriers faced, positioning them as existing in union.

Article 10 (Jones, 2019) positions autistic people as the experts in the topic, whilst acknowledging the dichotomy between the two narratives often portrayed in the media. Positioning the media as influential in views of autism is identified, focusing upon representation of the community, rather than a fixed view that reinforces stereotypes.

Similarly, Leslie (2019) positions the media portrayal of autistic people as important, both in seeing people like yourself on TV and influencing assumptions and stereotypes. In the article, several examples of TV shows with autistic characters are provided, evaluating these based upon the perceived expertise of the consultants. Authenticity is positioned as important, with autistic writers and consultants being valued more highly.

#### **5.3.2.5 Stages 5 & 6: practice and subjectivity**

Gill (2019) presents an account of a distressing event of violence which is likely to evoke an emotional response in the reader. This negative may also infer that autism is correlated to having these experiences, making autistic people vulnerable to adverse experiences. The article is positioned to reflect an event which had several actors, the autistic 'victim', the aggressor, and then the school who provided a comment. It may be viewed that the incident was preventable or expected, thus positioning blame and responsibility onto the school. The available subject positions

present this as an article of a bad experience in which autism was what prompted this individual to be targeted.

Within article 2 (NA, 2019), Chelsea's experiences of the project are provided by others, as such, readers may question why she did not make her own comment. Implications of this could be that autistic people are viewed as unable to contribute. Whilst utilising a parent's comment is a move from the reliance on professionals as experts, this may reinforce the hierarchy of voice and prioritising those of adults. Through focusing upon developing friendship, it challenges the assumption that autistic people do not want friends.

O'Boyle (2019, article 3) draw on practical applications to specific professions, positioning the topic as something for expert consideration. The author (O'Boyle) opens the article citing autism being '*a condition associated most strongly with men and boys*', which may encourage assumptions and stereotypes to perpetuate society without challenge. However, following the introductory comment, experts are described and thus the remainder of the article is composed of direct quotes from several '*experts*'. Through citing of the project and supporting quotes portray the positive benefits. Though, as this is from a professional stakeholder, with potential investments in the project being perceived positively, subjectivity may be present. Utilising quotes from autistic people involved would have provided some authenticity to these claims, as well shifting the focus to autistic people, rather than professionals. Utilising the '*special needs*' lexis within the title may elicit a strong emotional response from readers as neurodiversity advocates and the disabled community dislike the term and the connotations it eludes. Focusing upon diagnosis and other medicalised language further goes against the preferences of the community in which the article describes.

Article 4 (Birrell, 2019) presents possibilities for action for the reader to find out more about the topic. Utilising terms such as '*we*' positions the author as being within the community being described, as well as explaining the clear opinions and views

portrayed. The subjectivity within this article may be acknowledged by the location of the article being in the '*opinion*' section of the publication. Whilst more socially driven models are acknowledged, language choices, such as '*person with autism*' go against the community's preference, which may lead to questions of how much the author is aware within the topic area. Including a well-known individual, Greta Thunberg, it presents a practical purpose for society due to the wider media coverage, with it being a potential hot topic and thus aiming to elevate the article to of equal societal importance.

Hill (2019, article 5) has practical applications, namely, to encourage the readers to seek the book and read it. In addition, presenting the clear instructions of where to go for more information, it closes the opportunity for society to avoid the topic area. This article features within '*life & style*' which may influence the perception of the article and the weight of the voices portrayed within it. The journalist does utilise quotations within the article, though in comparison to previously cited articles, autistic people and their views are embedded within the narrative. Providing a clear statement in the concluding paragraph reinforces the action that needs to occur, as well as who needs to act '*society has to change, not autistic people*'.

Drawing on wider discourses (see stage 2), Nolan (2019, article 6) describes wider issues, such as delays as receiving a diagnosis to give a background to why this would constitute news. Readers may come to their own position on the title because of their worldviews. Specifically, two interpretations that stand out are that the increased recognition of autism in females is the causal influence on the increase into diagnostic rates, and that females would not be diagnosed previous because of perceptions of '*high support needs*'. The subjectivity from the article may stem from the authors position as part of the community, being cited as an autism campaigner. Due to the expertise attributed to the author, there may be a level of influence had on the reader, specifically when considering language choices. Utilising person first language '*girls with autism*' may influence readers own language use. Whilst autistic people are not unanimous on language preferences, the community overall utilise the language of autistic person.

Article 7 (Worth, 2019) enlists a clear practical application through the '*practical tips*' cited at the end of the article and therefore presents a likely trajectory of actions resulting from reading this article. The response generated by the reader depend upon the perceived importance and relevance of the topic for them. Further, the value of contributors to the article, such as academic researchers, may influence the weight of the information shared. When introducing the academic contributor, the author describes their role as '*one of those trying to help the research catch up*', which positions the contributor as someone with expertise. As this article was published in an educational supplement, it is likely that the target audience are educational professionals, and thus linguistic and discursive strategies will reflect this. Describing how '*we know with some confidence that autistic girls have mostly been left without a diagnosis*' in the opening sentence clearly situates the position of the article on the discursive object, autistic females. This is enhanced through enlisting direct quotes from Dr Sedgewick that reinforce the topic areas being discussed.

First considerations of article 8 (Leake, 2019) present a practical application to those in a specific profession, doctors. Though, the categorisation of the article as '*news*' may indicate that is something wider society should be aware of. The title presents a subjective view of the most important fact for the reader to know, that there has been a failure, as well as the medical focus having the potential to be relatable. This is likely influenced by personal experiences and the agenda of the publication of the author. Speculation within the article as to why females can go undiagnosed, specifically how '*the symptoms of autism in girls can be subtler...*' presents an opportunity for the reader to form an opinion, as well as acknowledging the real-world applications. Similarly, to other articles, diagnosis is positioned as being the most important factor, with inferences that the challenges one faces are eliminating upon getting a diagnosis. This article overall focuses upon the procedural element of diagnosis in females, rather than post diagnosis experiences and the experiences of autistic females about their views. Utilising academic supporting quotes may authenticate the topic as they are perceived as higher up in hierarchy than other potential contributor, such as autistic people.

Silverman (2019, article 9) presents a unique article for consideration as it made up entirely of quotations from an external source. It was not clear if the quote choices and order of these were true to how they were told, and thus, may be subjective to the interpretation of Silverman and the purpose of the article. Practical applications of this article may include two branches, which likely depend on the readers interpretation and wider worldviews. It may be perceived that the quotes represent a mother proud of her daughters' achievements, using these to increase awareness. In comparison, it may be inferred that this is an attempt to gain attention, reacting to jealousy, or wanting to be involved with the topic due to its increase in discussion in mainstream media (due to Greta Thunberg). As quotes provide specific examples of how autistic people experience the world, '*being autistic can make embarrassment less likely*', these may be generalised to all autistic people. Again, through featuring within the '*news*' section of the publication, it would suggest that the author considers it of importance to a wide audience and that it is something with a current application.

Through descriptions of autistic people across a range of media, the reader is likely to relate to some of the topics presented in article 10 (Jones, 2019). The personal investment of the author is likely to affect the way that the discursive object is presented, with an overall negative view of the understandings within society. Describing stereotypes and assumptions gives the reader clear information which acts to inform with the hope of influencing practice. The level of subjectivity is enhanced as the author has a personal investment, though, that may be counteracted by it featuring within an opinion supplement. Potential effects of the opinion supplement could be that it is an ongoing discourse without a specific incident for the reader to engage with, as well as the role of the categorisation of the value given by the audience to the information provided. It is worthy of consideration that the inclusion of this article gives autistic people a voice that permeates society, rather than being excluded or side-lined to specific audiences. The personal expertise that the author attributes may be valued and act as a relatable element for readers. On the other hand, it may be perceived that this was written due to a personal frustration and as such does not require action by the reader.

Embedded within the discourse of article 11 (Leslie, 2019) is the view of autism as a '*problem*', therefore actioning practice that aims to resolve this. Practical applications to the readers world are enhanced through specific examples of media outlets where this topic is relevant. Females are not specifically discussed within the article, however, because of the perception of the male dominance, they may be missed, or misrepresented on television. The contributions from other sources align with the general position that television has an '*autism problem*'. This overall position influences the possible trajectory following reading the article, specifically, aiming to persuade readers to internalise the information and be aware of examples in their lives.

## **5.4 Discussion and synthesis**

The aim of this section is to summarise the main findings of this discourse analysis, consider their meaning and any implications. In addition, strengths and limitations will be discussed, in addition to ways in which future research could be directed.

### **5.4.1 Central findings**

Conducting an analysis using the same criteria across two timepoints enabled comparisons to be made. Overall, it appears that in 2019 the articles reflected a wider awareness of the female specific experiences, whereas those in 2015 more frequently focused on a single event. With both years' datasets quotes from a range of sources were embedded. These ranged from academics, educational professionals, families, and autistic people. The perception of expertise featured in both timepoints, though in 2015 this was positioned as being professionals and adults, compared to a shift in 2019 to more real-life experiences and autistic involvement. Another interesting finding in the 2019 data set was that first-hand accounts from autistic people were included alongside professional's thoughts, in comparison to second-hand accounts, for example from parents, in the 2015 articles.

Autistic authors in both timepoints were more closely aligned with the social model of disability, drawing on more emotive language and personal experiences. In the 2015

dataset, where articles focused upon a specific incident with a company or group, an opportunity to comment was given, with some declining to respond.

The overall position of each article was evaluated, with an overall view that these fell on a spectrum from aligning strongly with deficit driven beliefs, to those that view autistic people as experts and a social model of disability. Compared to the 2015 dataset, 2019 appears to be further along the spectrum (towards the social model of disability). Nonetheless, the language surrounding ‘diagnosis’ and ‘condition’ was identified irrespective of the timepoint, with person first language being the most frequent, *‘person with autism’*.

The positioning with individuals varies across the articles, with some narrating the personal experiences an individual has faced, including their own comments, others utilise these to present a story, with comments about its impact being provided by those in the individuals’ wider network. Without using direct quotes, where possible, from the individuals included in the narratives, it positions them on the outside, reinforcing views of otherness and not able to contribute.

#### **5.4.2 Research questions and aims.**

The findings from the data from the two timepoints presents themes of how autistic people and autism is portrayed in the media. Autistic females varied in how they were portrayed, though this was often linked with the topic of the article and the likely purpose of it being written. Each of the research aims will be revisited.

*To consider the context in which the articles are published and the impact of this on how autistic females are viewed or portrayed in the media.*

Articles were published in a range of contexts and had a purpose attributed to them. Where autistic people were included in a narrative of something bad happening, autism was often positioned as the catalyst. In comparison, the context of a larger number of articles in 2019 presented a more general overview of female experiences. Further, acknowledging the assumptions made in mass media and society about autistic and neurodiverse people provided a context for some of the narratives.

*To consider the language used to describe autistic females and the characteristics or behaviour associated with this.*

Overall, language choices varied both between articles and within an individual article. One of the main themes when considering language choice is whether someone is referred to as autistic person, or person with autism. Another consideration is the prevalence of medical lexicon and language aligned with deficit models such as 'disorder'.

*To consider how wider concepts, such as models of disability, and societal perceptions of autistic females can be identified in this discourse analysis.*

Each article aligned in some degree to a model of disability, with some making this position explicitly clear, whereas others it was implicit through other linguistic and discursive choices. Decisions about the narratives provided in the articles in some instances reinforced inaccurate perceptions, whereas others presented a challenge to assumptions. When describing the experiences of autistic females, most of the discussion overall focused upon the levels of diagnosis, such as the ratio of males to females receiving a diagnosis.

*To identify and evaluate the sources used within articles to provide quotes or accounts about gender and autism, specifically in females.*

Quotes provided include those from academics, directors and professionals in autism societies and organisations, educational professionals, and autistic people. Some articles relied more heavily on direct quotes from professionals, which is assumed to be to increase the credibility of the article. Whilst autistic people were sources within some of the articles, this was not as prominent as academics and educational professionals. Nonetheless, the views and experiences of autistic people may have been encompassed within quotes and contributions from close family members such as parents (this was more prevalent in the 2015 dataset).



### 5.4.3 Strengths and limitations

Overall, there were some key strengths to the analysis. These included using a clear retrieval strategy and structured analysis to identify the articles to be included. Focusing upon the UK as the publication location was deemed appropriate due to the variability of perceptions across different cultures and locations.

In addition, some limitations could be identified, namely the use of a single reviewer throughout the data collection and analysis processes. Whilst there were clear criteria to aid the refinement of articles to be included, as well as reflexive reviewing of the process with academic supervisors, it may have been beneficial to have an additional reviewer. The benefits of this would have been to provide validation of themes and the inclusion of inter-rater reliability, though, this may not have been an appropriate fit with the epistemological position of this thesis. With the focus on surfacing the experiences of autistic people, a second reviewer may have resulted in a conflict in how discourse was interpreted, thus, impacting theme development. Should this method be replicated in future, where a second researcher be involved in the refinement and analysis, the selection of such individual would need careful consideration. A researcher's personal worldview and experiences of the topics included (being autistic) may have influenced how the articles and discourses were viewed. There were only 11 articles included in the final analysis, which may be viewed as a limitation in identifying themes and discursive strategies in news media. Further, due to the small number of articles being included, wider considerations of the purpose of the publication and its influence on discourse was limited.

In comparison to previous reviews, such as Billwalla and Wobling (2014), the number of articles included was significantly smaller. However, this was balanced by the specific time that articles were published, as well as a wider corpus of publications, rather than restricting to a single publication. The benefit of the decision to include all national publications was to ensure the findings could more accurately represent views among society in each time. Due to publications having links with political and philosophical worldviews, it is likely these will influence the discursive objects and

possibilities for action included in articles. On the other hand, as there were only a small number of articles from each publication, exploring the influence on the publications on the results was beyond the scope of the study. Focusing upon a single time enabled the analysis to remain focused, with results presenting a picture that is associated with that time, and therefore cannot be generalised to a wider time.

As with many news publications, the content is driven by experiences and narratives in a single time. The decision to publish an article is influenced by the wider context of society and other events that are being reported upon. To further enhance the findings, an exploration of articles which were rejected or side-lined would be beneficial. The research questions for this analysis were broad due to its exploratory nature. However, this may be viewed as a limitation when looking at a specific area of discourse. More guided analysis, for example focusing upon the use of contributions from secondary sources, would have resulting in other themes and wider discourses being missed.

#### **5.4.4 Reflections and implications**

There are several ways this analysis could be developed and expanded to present a broader understanding of the positioning and views of autism and females. Due to the single time defined in this analysis, it would be beneficial to further explore other time periods to draw longitudinal comparisons about the way in which autism in females is portrayed in the media. In addition, analysis which focused upon disability and inclusion more broadly may enhance understandings of the way autism is viewed.

Whilst the primary purpose of completing this analysis was to inform the future direction of the thesis, some key findings may be applicable to wider contexts. The way autism is positioned in news articles may give a wider awareness of how it is viewed in society. In addition, as news articles have been shown to influence perceptions, findings from this phase may guide attempts to increase awareness and challenge stereotypes.

In relation to the next stages of the thesis, this analysis has reinforced the need to view experiences and accounts as accurate at that time, whilst also acknowledging

the influence of one's worldview on the discursive objects and opportunities for action provided. Further, ensuring that individuals can comment and share their own experiences is of paramount importance when exploring experiences. When designing the next phases methodology, a primary focus should be on ensuring that they allow for meaningful participation for individuals in a way in which they are comfortable. In addition, the influence, and views of secondary bodies, such as parents, practitioners, and education providers, gives a wider context to the perceptions that exists in society. Gaining an understanding of these, through engagement and cooperation between various groups of people is likely to result in an in-depth understanding which can generate change. The broad range of experiences for autistic females could be identified through the discourse analysis, therefore, further work should aim to encompass both areas of success, and areas needing to be developed.

#### **5.4.5 Summary**

Overall, this chapter identifies a range of discourses and possibilities for action arising from the individual articles which may indicate the views and perceptions of wider society. Through the large audiences these publications likely attract, autistic females gain representation, with the academic advances in understandings reinforcing the importance of the topic area.

## **Chapter 6: Phase three**

### **DEVELOPING THE PROFILE FOR AUTISTIC TEENAGE GIRLS:CO-PRODUCED WITH STAKEHOLDERS**

#### **6.1 Introduction**

The primary purpose of this chapter is to present the empirical phase of the study through each of the cycles undertaken. A reflective approach is taken throughout this chapter as stakeholder engagement influenced the development of the phases. The first section of this chapter provides a synthesis of literature in response to emergent themes in prior chapters. Then, the phase's design is presented, drawing on the underlying assumptions and approaches set out in chapter three to develop the one-page profile to focus specifically on autistic teenage girls. The results section includes a summary of the discussions at each cycle of the phase, embedding stakeholder quotes throughout. A version of the profile was created, along with stakeholder produced information to provide a context to the topic area. This version of the profile and the stakeholder produced context were combined to form a report that could be shared. Three key themes were highlighted, including the importance of a collaborative process, ensuring the autistic person is positioned in the centre, and the adoption of the profile as a living document. To conclude the chapter, an analysis of the findings are presented, linking back to the literature, and drawing on theoretical concepts to support interpretations made.

The term stakeholder is used throughout this chapter to reflect the collaborative nature of the design, as well as being preferred by the autistic community involved in research. For a discussion of the role of stakeholders see section 6.2.1.1.

##### **6.1.1 Transition between phase 2 and 3 of the thesis**

The discourse analysis (chapter 5) was enlisted due to the restrictions of the Coronavirus pandemic as it enabled the study to progress within the time frame of the PhD. The data from both this, and the scoping review (chapter 4), highlighted positionings of autistic females and their experiences on a continuum, from academic literature to news media. Following this, empirical data collection was designed to respond to this in a way that would be feasible within the public health restrictions, whilst also prioritising surfacing autistic teenage girls' perspectives that would

contribute to understandings of this complex social discourse. With this chapter being the third phase of the thesis, making the decision to utilise one specific tool (the one-page profile) within the workshops was a result of time-constraints for the completion of the thesis. Utilising the tool acted as a mechanism to generate discussions and ensured that the thesis had useful applications to stakeholders and their communities. An alternative approach would have been to enlist stakeholder input on how the empirical work should be framed and the utility of a tool such as the profile, though this would have been at the detriment of producing something applicable to the stakeholders and the communities that they represented.

## **6.2 Synthesis of literature**

### **6.2.1 Stakeholder involvement**

Within research, the dominant approach is one in which autistic people are the object of the research, rather than being part of a collaborative process (Oliver, 2013). This is described as a 'traditional knowledge transfer model of research' (Parsons, Kuill, Good & Brosnan, 2020, p.203), conceptualised as prioritising specific ways of knowing within academic communities (Parsons *et al.*, 2015).

#### **6.2.1.1 Current thoughts**

Within the context of technology and autism, Parsons *et al.*, (2020) provides a suggestion of stakeholders who should be involved in collaborations and co-produced research. These include autistic people and their families, professionals, specific practitioners, and researchers from a range of disciplines and backgrounds. The role of digital networks has featured predominantly within the neurodiversity movement, primarily online and including autistic self-advocates, ensuring the message of the value and importance of autistic identities is visible and geographical location does not exclude individuals who wish to join the movement (Kapp *et al.*, 2013). Davidson (2008), along with Brosnan and Gavin (2015) take this further by describing it as an enabling feature to empower voice, advocacy and participation that may otherwise not be possible. This self-advocacy has been widely cited in the progress made in the disability field over the past thirty years (Oliver, 2013).

Self-advocates and researchers alike have raised concern about the influence that people without autism have in guiding the research agenda, along with a lack of equality between the views expressed by different stakeholders (Milton, 2014; Robertson, 2009; Woods *et al.*, 2018). Pellicano, Dinsmore and Charman (2013) enlisted a large-scale survey to address this, which included autistic people, their families, and academic researchers. Findings identified a conflict between the research receiving funding, namely medical research, and the research that autistic people felt was needed; education, support, and high-quality services (Pellicano, Dinsmore & Charman, 2013).

This considered, Nind (2014) identifies that there has been a shift within autism research to one that is inclusive and co-constructed, whereby autistic people are positioned as collaborators rather than participants. The description of this type of research promotes the shift in the role of stakeholders from subjects to partners in decision making, which in turn, is likely to generate research that aligns with the priorities and needs of the autistic community (Chown *et al.*, 2017). Discussions around research agendas in autism research have been presented by Parsons and Kovshoff (2019), with co-construction of these allowing for a range of voices, ideas, experiences, and knowledge to be shared.

#### **6.2.1.2 Needs analysis**

A needs analysis or needs assessment has been proposed by Soriano (2013) as possible method for exploring a range of stakeholder perspectives. Whilst definitions can vary between citing's, a general view considers a needs analysis to use:

*“a problem-solving process for the purpose of collecting, organising and presenting information that describes the needs of a target population and evaluates their importance relative to remand”* (Powers & Knapp, 2010, p.120). Whilst not used within this phase, a needs analysis has some components that are transferable namely the focus on the individual and its position as a proactive rather a reactive document.

The purpose of including different stakeholders is to encourage a collective agreement that comes from the views, in turn helping to identify future research priorities and the way inclusion and collaboration is disseminated on a wider scale (Saggers *et*

*al.*, 2019). The use of a needs analysis allows different stakeholders to present their views equally as well as acknowledging the various roles that need to be considered (Grimshaw *et al.*, 2012; Soriano, 2013). The use of this approach draws upon understandings of translating knowledge into actions, a practice which is commonplace within academia (Grimshaw *et al.*, 2012). When considering the field of autism, an increase in research is hoped to benefit all stakeholders involved (Pellicano *et al.*, 2014). However, attention has been drawn to gaps highlighted in research and practice, with new research being urged to address this disparity (Saggers *et al.*, 2019; Grimshaw *et al.*, 2012).

#### **6.2.1.3 Rights-based versus needs-based approaches**

In the specific field of education, the inclusion of autistic students draws upon two contradictory perspectives which are rights-based, and needs-based (Ravet, 2011). Whilst education is not the focus of this thesis, Saggers *et al.*, (2019) provide a valuable insight into the views and beliefs that may emerge through data collection, specifically through the educational professionals' inclusion. A rights-based approach highlights the importance of both academic progress and social inclusion for all students, aiming to disperse educational segregation (Centre for studies in Inclusive Education, 2008). In comparison, a needs-based perspective focuses upon ensuring that specific provision for unique and distinctive needs is preserved (Lindsay, 2007). Consequently, there may be confusion for stakeholders about which theoretical view to align with, specifically when understanding and interpreting what inclusive practices are (Ravet, 2011). In addition, this may result in variations in the way this is understood and actioned within educational settings (Saggers *et al.*, 2019). Despite this, integrated approaches have been proposed, emphasising the importance of an individuals' needs when considering inclusion and actions taken (Ravet, 2011). This has been discussed within the neurodiversity movement, which has emphasised valuing strength-based approaches and valuing collaboration that includes autistic people (den Houting, 2019).

#### **6.2.1.4 Autonomy**

Within the theoretical reflection on approaches to stakeholder engagement is the concept of autonomy. Autonomy has been described as the focus of a discussion

rather than an object to be studied (Spath & Jongsma, 2020). Bloom (2009) describes how the need for support may act as a barrier in becoming autonomous, through assumptions imposed by wider society. These include perceptions that autistic people lack self-awareness and struggle to understand social structures and expectations (Livingston & Happe, 2017). Linking to a one-page profile, Spath and Jongsma (2020) describe the alternative view that autistic people can prioritise their values and can make choices, expressing preferences. Through tailoring the one-page profile to meet the individual's needs, it can be positioned as a meaningful task relating to them that they can focus on and contribute to (Brownlow, 2010; Sjodin, 2015).

Overall, stakeholder engagement and reflecting on the priorities in this field aims to develop the knowledge translation between stakeholders, as well as actively listening to views of the autistic community (Pellicano *et al.*, 2014). More broadly, this contributed to generation of well-informed research that reflects and responds to the needs of autistic people, as well as appropriate dissemination into policy and practice (Pellicano *et al.*, 2014; Saggars *et al.*, 2019). Previous publications that include stakeholder perspectives being involved have demonstrated a mix of results (Pellicano *et al.*, 2018; Roberts & Simpson, 2016; Stokes *et al.*, 2017). However, Roberts and Simpson's (2016) literature review did highlight some frequent themes, such as varying levels of knowledge and appropriate understandings of the varied of characteristics and challenges that may be presented.

#### **6.2.1.5 Public engagement**

Public engagement is considered a key factor in translating research to practice and embedding accurate understanding among society, however, when considering the field of autism, it has been inconsistent (Elsabbagh, Yusuf, Prasanna, Shikako-Thomas, Ruff & Fehlings, 2014). Due to this inconsistency, two examples can be identified. The first, includes the role of families and advocates in supporting research and contributing to experts' understanding, including fundraising (Silverman & Brosco, 2007). In comparison, a disconnect between scientific research and societies priorities has been identified (Elsabbagh, 2012; Young *et al.*, 2002). Specifically, this focuses upon the way the needs and priorities are understood within different communities and how these are reflected within policy and decisions made by



governmental organisations (Khan *et al.*, 2012; Pellicano & Stears, 2011). Public engagement has been described in several ways, however, the core principle cites ‘that those impacted by the research have a say in how the research is undertaken...’ (Elsabagh *et al.*, 2014, p.774). This drives the move to active engagement, which also involves shaping research priorities and the design of subsequent research methodology (Elsabagh *et al.*, 2014). Exploring current tools available in the sector, with a specific focus on the participatory and coproduction approaches identified the one-page profile as a suitable starting point. Specifically, the Welsh Government’s publication and guidance document was adopted to enable findings to be linked to the specific political and governmental position of the stakeholders involved (Welsh Government, 2015a, 2015b, 2015c).

### **6.2.2 One-page profile**

The one-page profile is a tool that provides individualised information about an individual to those around them (Welsh Government, 2015b). Swain and Waddington (2020) describe how the tool is used widely to facilitate learner-centred planning and information sharing. Furthermore, they are mentioned in England’s Special Education Needs and Disability code of practice (Department for Education and Department of Health and Social Care, 2015).

Learning support plans use a similar motivation to help ensure individuals have a consistent level of care that is tailored to their needs (Hagner, Kurtz, May & Cloutier, 2014). Similarly, to one-page profiles, they are evolving documents which should be modified and updated regularly (Blair, Lee, Cho & Dunlap, 2011). A UK study by Brodrick *et al.*, (2011) explored the use of these, with positive feedback about their use. However, limitations in staff knowledge and understanding of these was described, specifically in acute settings when receiving unscheduled care (Brodrick *et al.*, 2011). These findings were consolidated through additional research, for example, Bell (2012), who also identified experiences of these not being read even if they were recognised. Strong leadership was cited as being responsible for the implementation of these tools, as well as ensuring stakeholders continually develop and review the information included (Damschroder *et al.*, 2009; Fixsen *et al.*, 2013 in Heifetz & Lunsky, 2018). An organisational or sector commitment to any innovation is necessary

to ensure that the benefits can be realised (Damschroder *et al.*, 2009). Support and the backing of management has been linked with increased productivity and positive outcomes, with Fixsen *et al.*, (2013, cited in Heifetz & Lunsky, 2018) citing these being five times higher than where management demonstrate a low commitment. Findings from the health sector provide useful considerations for this phase, specifically in how to implement them. The role of professionals, service users and the community should come together to gain a consensus about its use, for example, the topics to be covered within it (Heifetz & Lunsky, 2018).

### **6.2.3 One-page profile in Wales**

The one-page profile described in this chapter is taken from the Welsh Government (2015c) document 'Person-centred practice in education: a guide for early years, schools and colleges in Wales'. Further guidance surrounding person-centred approaches is provided by further publications focused upon organisational development and person-centred reviews (Welsh Government 2015a: 2015b). The publication falls within the Additional Learning Needs (ALN) transformation programme, scheduled to begin in a phased basis in September 2021 (Welsh Government, 2017: 2018: 2019). This legislative framework introduced through this act relates to children and young people from birth until age twenty-five, with 'additional learning needs' replacing the use of special educational needs (Conn & Hutt, 2018). The one-page profile was used as the basis for the workshops to generate discussion, more detail is provided in section 6.3.6.1.

### **6.2.4 Conclusion of section**

In reviewing previous literature, an overall gap appeared in how participatory methods are used, specifically, the inconsistency and variability in how and when autistic people are consulted and engaged with research processes. Autistic involvement provides a mechanism to surface alternative perspective to the predominant contributions from professionals in academic literature. Furthermore, participatory and person-centred practices present in practical applications, including one-page profiles.

To address this, a co-produced (Stark *et al.*, 2020) phase was completed that sought to review the one-page profile to be used for autistic teenage girls. The tool acted as

a mechanism to generate discussion and frame the research questions. In addition, utilising this tool was beneficial due to its prominence for professionals in Wales. It also shares features with other tools in use, specifically its structure and purpose.

### **6.3 Method**

A participatory online phase was conducted to explore the one-page profile for use with autistic teenage girls in Wales, influenced by Stark *et al.*, (2020). This qualitative phase sought to answer two research questions and five aims. The principles of participatory research and co-production highlighted in chapter three were employed to guide this phase.

#### **6.3.1 Research questions and aims.**

The research questions were developed from the Scoping Review (Chapter four) and the Discourse Analysis (Chapter five). Specifically, the predominance of the use of standardised measurement tools in previous research (as identified in the Scoping review) influenced the development of Research Question 2, and the influence of how autistic people are positioned on assumptions and decisions made about their social world (as identified from the findings of the discourse analysis) was used to develop Research Question 1.

##### **6.3.1.1 Research questions:**

- How do stakeholders' positions influence their completion and evaluation of the one-page profile?
- Is the one-page profile and guidance purposeful and beneficial when used for autistic teenage girls? Does it need be altered to become more effective?

##### **6.3.1.2 Research aims:**

As detailed below, the aims of the present phase expand upon ideas of positioning of autistic teenage girls (Harre *et al.*, 2009) through contributions from a variety of stakeholders. This is focused upon the completion of a one-page profile,

demonstrating the different opinions and priorities, whilst viewing these as equal, valid and important. The aims acknowledge and support the principles of co-production (Start *et al.*, 2020) and the iterative nature of the thesis. The aims provided a scaffold for the approach to data collection, supporting the creation of data with stakeholders, rather than setting out aims of achieving specific tasks.

The research aims were:

- To use the self-completed one-page profiles in phase one to explore how autistic stakeholders position themselves.
- To explore how professional stakeholders interpret a case study on how to complete the one-page profile, specifically focusing on the information they select as important, and the role of positioning.
- To facilitate an open discussion between stakeholders about the needs of autistic teenage girls and the perspectives of what is important to them.
- To either amend and edit the tool and guidance that is currently in use (one-page profile) or create a new tool and guidance that specifically considers autistic teenage girls (13-18 years old).
- To encourage co-production between the researcher and stakeholders to generate findings applicable outside the academic research setting.

### **6.3.2 Stakeholders**

There were two stakeholder groups: a stakeholder group of people identifying as autistic, and a stakeholder group of people currently employed in across the fields below were involved, reflecting a potential range of experiences of supporting or working with autistic females. There was no restriction of the age of these females as this would have significantly reduced the stakeholders available to participate.

- Education.
- Health.
- Social care.
- Research.
- Academia (Master's level and above).
- Policy.

- Advocacy.
- Third sector, voluntary and charity

The inclusion criteria were predominantly made up of demographic factors, and as a result, exclusion was based upon an individual not meeting the inclusion criteria. Clear inclusion criteria were provided for all stakeholders that expressed an interest in participating. Having access to an electronic device to participate and an email address to be contacted through was a physical inclusion criterion due to the solely online method of data collection. The remaining inclusion criteria was based upon demographic factors for each of the groups, with a geographical location of Wales being applicable for both.

For the autistic group, stakeholders needed to be:

- Autistic (preferably formal diagnosis).
- Aged 13 or over.
- Female (sex assigned at birth).
- Living in Wales.
- A parent or guardian of an autistic female aged 13 or over in Wales.

From this point, the autistic group are referred to as group 1, and the professional stakeholders as group 2.

### **6.3.3 Recruitment**

Recruitment was undertaken through Twitter and Facebook, where a single bilingual advert (as an image) was shared, along with a standardised message (Appendices 8 & 9). This was easy to read and included key information about the study within it, for example, the stakeholders sought.

This image along with additional information was shared with identified contacts in various positions in Wales, as well as generalised recruitment. This included:

- Additional Learning Needs / Diversity contacts in all councils in Wales.
- Disability or Support services in all University's in Wales.
- Academic researchers in Wales identified through institutions research pages.

- The researchers online Twitter and Facebook accounts.
- Within Facebook research community groups (with permission of the group owner).
- Within Facebook autistic communities (with permission of the group owner).
- Charity and voluntary organisations with links to autism in Wales.

To ensure the recruitment process was managed, a record was kept of all communications, including the method of communication, date of communication and any response received. Initially, these contacts were focusing on sharing the information across networks and colleagues who may meet the inclusion criteria. Communications with individuals about participation were similarly recorded, with expressions of interest via email being categorised into a subfolder to allow easy access. Standardised email responses were dictated prior to recruitment to ensure consistency of information and facilitate timely responses.

The number of stakeholders desired for the phase was between twelve and fifteen across the two groups: autistic and professional. Initially, recruitment was more successful for the autistic group, leading to focus of communications to be the professional group, which was successful.

Following recruitment, stakeholders had direct email communication from the researcher providing relevant information, including arranging the date and times. All stakeholders had contact details for the researcher and supervisory team should they wish to discuss anything – this included phone numbers. This communication included the sharing of the information sheets and facilitating the consent forms to be completed (see appendices 15-22 for information sheets).

#### **6.3.4 Protocol**

Prior to submitting an ethical proposal, a protocol was written that outlined the various cycles of this phase, including the planning, recruitment, data collection, and analysis stages. Within this, the importance of positioning arising from the discourse analysis was acknowledged, specifically in how different stakeholders view the experiences and needs of autistic teenage girls. This protocol also established that the term

'stakeholder' would be used to describe the individuals contributing to the study, rather than the term participant.

Once it was decided that co-production (Stark *et al.*, 2020) and workshops were to form the structure of this phase, the researcher met with three colleagues who have used this approach to gain insight into its use in various topic areas. These meetings were informal online discussions starting with the familiarisation of their experiences of the method, things they found beneficial and challenges they had faced. Further, the researcher described their study protocol to guide the discussion further.

The first of these colleagues was a PhD researcher who had used online workshops with a broad range of professional stakeholders in planning hospital discharge. The second had used coproduction in face-to-face workshops in the field of dementia. The final colleague had used coproduction in face-to-face workshops to explore lived experiences of work and welfare. These individuals were identified through a discussion with the research team of where the method had been used in topic areas differing from the focus of this research. They were initially approached by email to ascertain if they would be willing to an informal discussion, with a mutually convenient time for this being agreed.

The discussions with the above three colleagues were useful in making specific decisions about the format of data collection, considerations for online data collection, (as the data collection phase coincided with covid-19 related restrictions to in-person research), and which approaches would be best suited to optimise stakeholder engagement. An additional benefit to meeting with these colleagues was that feedback was given about the current protocol and contributed to decisions made about smaller aspects of the research design. With the range of approaches to co-produced workshops available to the researcher, discussions with these colleagues aided in tailoring the approach for the aims of the study. An example of this is the discussion surrounding how stakeholders would be grouped and involved in the research, with a decision being made that two groups should be formed in the initial workshops, with these coming together in subsequent stages (for more details about the design of the workshops see section 6.3.6).

Overall, these discussions reinforced the need to be flexible, to consider the influence of an online approach across all aspects of data collection and the possible barriers that may arise when compared to a face-to-face method.

### **6.3.5 Online method and participation**

Online methods of participation can encourage hard-to-reach stakeholders to contribute (Baltar & Brunet, 2012), with other benefits of internet-based research including the ease of follow-up, greater geographical reach and easier data management (Epstein & Klinkenberg 2002; Evans & Mathur 2005; Fricker & Schonlau 2002; Gosling *et al.*, 2004; Umbach 2004; Wilson & Laskey 2003). Through informal discussions with stakeholders during the protocol writing phase, feedback highlighted the benefits of online workshops in enabling individuals to participate in a way they are comfortable, feeling more able to be honest and reducing the anxiety of participating in a project that may include sensitive discussions. This is supported by Hall, Gaved and Sargent (2021) who highlight the benefits of being in familiar surroundings and feeling comfortable when participating. Furthermore, utilising a chat function in parallel to verbal discourse can increase information covered and provide an alternative method for contributions from stakeholders (Dodd & Hess, 2020). Overall, context-specific ethical issues and measures to balance them were considered and defined within the protocol and ethical review processes (Hall, Gaved & Sargent, 2021).

Microsoft Teams was used as the data collection tool and platform to host the workshops in this phase. Teams enabled the researcher to screen share slides with prompts and information throughout the workshops. In addition, it facilitated written and audio comments, with these being saved and recorded onto the secure OneDrive. Each workshop was recorded through the application and stored on an encrypted and password protected folder. This was described in advance to stakeholders through the information sheet and consent form completed.

The Researcher was the primary facilitator present in the workshops but was supported in the second phase by additional facilitators to make notes and general group management tasks. Where additional facilitators were present, their role was explained in advanced of the workshops and again in the introductory sections. The facilitators were one of the project supervisors and a fellow PhD candidate within the



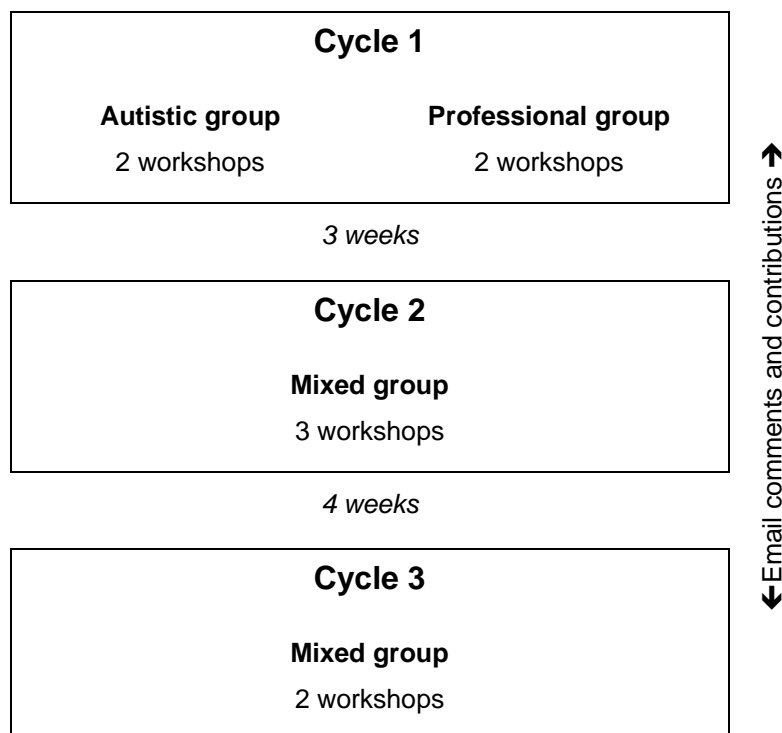
school. They were provided with a crib sheet of information relevant to their role and were given access to the secure OneDrive folder with the emergency contact information.

Once assigned to a specific group and slot, stakeholders were sent a link to the meeting, along with a guide to participation (see appendices 13 & 14). The stakeholder guide included instructions on how to access the chosen platform (Microsoft Teams) and tips for getting the most out of the workshops. It also included information about each stage of the research and an outline of the timings involved to allow stakeholders to prepare, this also included the duration expected. Through all phases of the online workshops, stakeholders were able to contribute through the chat function. This included commenting on the verbal discussions taking place and feedback on personal experiences. The functions of the online platform were described in advance via a stakeholder guide and revisited at the start of every workshop, for example, the hand raising function. Other 'ground rules' were agreed during the first phase and subsequently shared with all stakeholders.

To ensure researcher safety, the dates and times of data collection were recorded on a shared calendar among the supervisory team. This included the expected duration and number of stakeholders. The risk assessment included additional measures in place, such as emailing the supervisory team at the end of every data collection session to confirm all went well as there were no issues. For a full description of these measures see the risk assessment in appendix 35. A shared OneDrive folder was used to store confidential information pertaining to the project, including the emergency contact details for stakeholders should any issues arise. In workshops where there was an additional facilitator present, the workshop structure and prompt notes were shared.

### **6.3.6 Method**

A series of online workshops were scheduled across three cycles, with stakeholders' contributions guiding how these were used when considering the topic of one-page profiles for autistic teenage girls. Figure 7 displays the three stages and workshops conducted, with a full description of these commencing at section 6.3.6.1.



*Figure 7: A visual representation of the cycles in this phase.*

The first cycle utilised an interactive activity and open discussions to gather feedback on the one-page profile and wider topics (see section 6.3.6.1). This also had the purpose of guiding how the two further cycles be utilised, reinforcing the collaborative process embedded throughout the phase. Two streams of data were produced throughout all cycles. The first, any documents or products created with stakeholders and the second, recorded discourse and conversation. This method enabled the researcher to be flexible in response to stakeholders' contributions, thus acting as an iterative and collaborative process. Both streams of data presented a chance to consider positionality, a theme that presented within the discourse analysis.

The one-page profile is a document produced by the Welsh Government (2015b) to encourage person centred methodologies in young people's reviews of their educational, health and social care needs. This document is accompanied by guidance and examples of its use (Welsh Government, 2015c). It includes three key areas about the individual; what people appreciate about them (like and admire), what is important to them and how to support them. It is written in the first person for the individual to share their opinions, rather than interpretations of them by another

individual. This tool is not specifically tailored to autistic females; however, it is a tool cited by Welsh Government (2015a; 2015b; 2015c) as embedding person-centred approaches within the field of additional learning needs in addition to aligning with the researchers position and world views. Enlisting a widely available document was considered best practice as it was not influenced by the research team, as well as being a document that professional stakeholders may already be aware of. A further advantage of utilising this document was that it was supported by guidance specific to the geographical location of this phase.

The key points of the approach adopted in this phase were:

- That it allows for co-production and all stakeholders to be viewed equally.
- That it is specifically targeted at the sample group, utilising an iterative process throughout the phases of research.
- That the findings will be relevant for the stakeholders in the context that the workshops were completed within.

Due to the iterative method adopted, each cycle is described below retrospectively (see chapter 3 for an in-depth theoretical outline of the methods and positions adopted in this study).

#### **6.3.6.1 Cycle 1**

During this cycle, the two stakeholders' groups joined separate online workshops, with the activity being adapted for the group. Due to stakeholder availability, two times were arranged for the professional group and two for the autistic group. The activity was completed using personal experiences in the autistic group and the professional group were provided with a vignette case study as a prompt.

#### **Personal experience**

For autistic stakeholder, prompts (see appendix 27) were used to encourage them to draw on their own experience in what information they felt they would include if asked to fill in a one-page profile. Stakeholders were informed that the information shared would not be included in any write up of research findings. If stakeholders felt

uncomfortable sharing information about themselves, they were encouraged to share information that they considered to be useful and appropriate for the sub-headings.

### **Case study**

A case study created through Sedgewick *et al.*'s (2016) research was cited in Nasen (2016). This case study utilised the real-life presentation of a participant in research and therefore considered to reflect a case that professionals may encounter in practice. Furthermore, utilising a case study that was already published reduced the possible bias which would have presented should a case study be constructed purely for the purpose of this research. Social relationships for adolescent females in autistic and non-autistic samples were the focus in Sedgewick *et al.*, (2016), therefore, presenting closely linking topic areas to the present phase.

**Charlotte is a quiet, well-behaved 14-year-old girl in a mainstream school and has a diagnosis of autism.**

- Charlotte has some teaching assistant support for dyslexia and is in the middle sets for all her subjects.
- She feels as though she is struggling at school and feels isolated.
- She is permanently anxious about the quality of her work.
- She is expected to achieve good results and go to university – she just needs more support to access the social world of her peers, to develop the self-confidence to approach the challenges of school life, and to not be missed through her lack of challenging behaviours.
- She likes to sit at the back of class and doesn't put her hand up or answers questions.
- Sitting at the back of class allows her to observe her peers and plan her reactions according to what she sees other people doing, she may not work it out on her own.
- Her reluctance to answer questions comes from her strong perfectionism, as she does not want to attempt something she might get wrong, and even if she does know the answer, she feels too shy to open herself up to attention from her peers.
- She likes to follow rules and interprets instructions literally.

- She can be the last to laugh at a joke, as she waits until she is sure that everyone else is laughing.
- She may be quiet, but she is not automatically 'ok'.
- Charlotte's best friend is called Jessica.
- Charlotte has really enjoyed drama and acting since moving to high school. She appeared good at it so was offered a place at a prestigious youth theatre. This interest has now expanded to include the literature in the drama's she was involved with, so much so, she can recite large sections of her favourite Shakespeare.

*Box 1: The case study used within the first workshop phase (Nasen, 2016 p.6).*

This cycle allowed for stakeholders to build a rapport with the researcher, provide thoughts about the phase and key topics, and contribute to the group agreement that would be utilised in the subsequent cycles. In advance of the workshops the researcher prepared some discussion theme prompts to help guide the conversation, as well as providing an opportunity for free discussion or comment. The structure utilised PowerPoint to present the information, including the prompts, and was sent to stakeholders after the end of the workshop to allow for any additional comments to be sent afterwards. Figure 8 documents the prompts used for each of the two stakeholder groups.

<b>Group 1 – Autistic stakeholders</b>	<b>Group 2 – Professional stakeholders</b>
<u>Case profile activity</u>  Use your own personal experiences and how you would approach this if you were completing a one-page profile. <ul style="list-style-type: none"> <li>• <i>What people appreciate about me (like and admire)</i></li> <li>• <i>What's important to me</i></li> <li>• <i>How to support me</i></li> </ul>	<u>Case profile activity</u>  Which information from it do you view as important? <ul style="list-style-type: none"> <li>• <i>What people appreciate about me (like and admire)</i></li> <li>• <i>What's important to me</i></li> <li>• <i>How to support me</i></li> <li>• <i>Other comments?</i></li> </ul>

<ul style="list-style-type: none"> <li>• <i>Other comments?</i></li> </ul>	
<p style="text-align: center;"><u>Discussion – activity</u></p> <p><i>How did you find completing the one-page profile?</i></p> <ul style="list-style-type: none"> <li>• <i>What do you think is good about it?</i></li> <li>• <i>Can anything be improved?</i></li> <li>• <i>Focusing on autistic females, is it suitable / fit for purpose?</i></li> <li>• <i>Other comments?</i></li> </ul>	
<p style="text-align: center;"><u>Feedback / comments (open)</u></p> <p><i>For example...</i></p> <ul style="list-style-type: none"> <li>• <i>Thoughts about the importance of this study.</i></li> <li>• <i>Thoughts about the sample group (autistic teenage girls)</i></li> <li>• <i>Applications in your life?</i></li> </ul>	

Figure 8: Prompts used in phase one professional and autistic stakeholder groups.

### 6.3.6.2 Cycle 2

This cycle involved three workshops, each with a mix of individuals from the stakeholder groups. Again, the group agreement was presented at the start, as well as utilising an ice breaker. The key themes and discussions from each cycle 1 group were presented during the workshop providing the opportunity to seek clarity, gain additional perspectives, and to validate the researchers' interpretations as being correct. These summaries were provided by email before the second cycle, ensuring the stakeholders had a further opportunity to process the content and provide any comments or feedback. The next section of this workshop included a focus upon the guidance document for the one-page profile, which had been shared before the workshop. As the purpose of this project was shaped as creating a collaborative document, discussions focused upon the topics and information that would need to be included. The direction of the workshops, to co-create a document, was identified by the researcher through previous discussions. This purpose was shared with the stakeholders and agreed within the second cycle.

The final section of this cycle included an opportunity for an open discussion about the topic area and the stakeholders' thoughts and experiences. Standardised prompts were designed to encourage conversation and validate the researchers' interpretations, these were used in all slots of this cycles workshops. These prompts provided a structure to the session. Figure 9 details these:

Welcome Introduction Session Schedule Group agreement Ice breaker	
Summary of discussions in cycle 1	<ul style="list-style-type: none"> <li>• Professional session 1</li> <li>• Professional session 2</li> <li>• Autistic session 1</li> <li>• Autistic session 2</li> <li>• Professional and autistic overall</li> </ul>
Cycle 1 key themes	
Discussion of summaries and key themes	
<u>Topics and themes which may be included on the tool</u>  <i>These would be optional and prompts for people to use, rather than being a fixed format.</i> <ul style="list-style-type: none"> <li>• Description of topic or theme.</li> <li>• Example of the information to be included.</li> <li>• Any explanation to accompany theme.</li> </ul>	
Break – 10 minutes	
Construction of a tool, including how it will look.	
Discussion about guidance document, what needs to be included?	
Conclusion and explanation about phase 3.	
Questions	

Figure 9: The structure and prompts used in cycle 2.

During this cycle an additional facilitator was present within the workshops to make notes and validate the previous themes. These notes were shared following the workshop and discussed to aid the summary of the phase to be provided to the stakeholders. Further, these notes were utilised when writing up the narrative of data collection and exploring key themes.

A draft document was created and shared with stakeholders in advance of the final cycle, allowing for comments to be received before the workshop by email.

#### **6.3.6.3 Cycle 3**

This cycle took place over a period of four weeks. It involved two online workshop sessions for stakeholders to provide feedback on the draft document that had been shared by email. This presented another opportunity to ensure the researcher had interpreted themes and discussions appropriately, thus acting as a validation process. It was shared a week in advance of the workshop sessions with instructions of the purpose of this stage, for example, reviewing the definitions ascribed to terms in the document. In addition, stakeholders had the opportunity to provide email written feedback before and after this workshop. There was a set time of four weeks allocated to receiving comments and feedback, with workshops being held in the second week. Giving this amount of time was to ensure stakeholders were not overburdened by the task and had enough opportunity for their voices to be heard. Following this feedback period, the document was finalised and shared with all stakeholders via email along with full debriefing information. This debriefing including reminding stakeholders of how the final report may be disseminated and shared to a wider audience, with their anonymity being maintained.

#### **6.3.7 Welsh Language**

As the phase included stakeholders from Wales, it was important to ensure the use of the Welsh Language in this phase was made clear. Recruitment adverts, the information sheets and the consent forms were available in Welsh and English, with translation being completed by Canolfan Bedwyr. The stakeholder guide was also



provided bilingually. As the researchers first language is English, workshops were conducted in English, as well as any other direct communication with stakeholders.

### **6.3.8 Analysis**

Following each workshop, automated transcription through Microsoft Teams was utilised to aid in the analysis of the discourse. Once this had been completed, the researcher re-listened to the workshops to ensure that transcription accurately represented the content of the workshops. This, along with handwritten notes and memoing throughout the workshops were utilised to identify themes. In workshops with an additional facilitator, additional memos and notes were generated. Following each workshop, the supervision team met to discuss the workshops and identified themes, which acted as a process of validation. Analysis utilised positioning theory (Harré *et al.*, 2009) and thematic analysis (Braun & Clarke, 2006).

#### **6.3.8.1 Positioning theory**

The analysis of data produced through this phase is embedded in positioning theory (Harré *et al.*, 2009; Harré & van Langenhove, 1999). At its core, this aims to understand the dynamics of people's cognitive schemas and their relationship to social action and agency (Barnes, 2004). It focuses upon a particular context at a local level wherein these processes are made visible, often through discourse and embodied actions. Simultaneously, positioning theory recognises that embodied actions involve moral rights and duties (Harré *et al.*, 2009). In this way, beliefs and practices are grounded in rights and duties which emanate from cognitive processes that are contextually and temporally bound, resulting in the construction of meaning.

Deriving meaning from perceived and lived duties and rights presents people as socially positioned in a particular context, performing certain social actions and practices with meaning delineated through storylines (Harré *et al.*, 2009; O'Connor, 2007). Data from the workshops was subject to positioning analysis (Davies & Harré, 1990; Harré & van Langenhove, 1999), a stance that views the social world as a place of an interactive discourse between actors (individuals, groups, social institutions, and cultural practices), whose implicit and explicit patterns of reasoning and actions are

realised by means of their 'positioning' in relation to each other (Allen & Wiles, 2013; Harré *et al.*, 2009). Overall, positioning theory concerns to understand the dynamics of people's cognitive schemas and their relationship to social action and agency (Harré *et al.*, 2009; O'Connor, 2007).

Positioning theory was embedded within the thematic analysis, specifically, when identifying themes.

#### **6.3.8.2 Thematic analysis**

The first three stages of thematic analysis (Braun & Clarke, 2005) were used in the first cycle of data collection. The emergent themes then underwent stage 4 (review of themes) through presenting these to stakeholders for agreement and validation in the second cycle. Thematic analysis was considered appropriate as the purpose of the phase was to direct subsequent cycles, where identifying themes would be beneficial. In addition, using a structured approach ensured consistency when used for each individual workshop.

- Phase 1: familiarisation with data

Following each of the individual workshops, the researcher used the recordings, transcriptions, written chat contributions and notes to gain a familiarity to the data. Through this, written memos were added with initial interpretations of comments and possible emergent themes. In addition, through revisiting each workshop, the researcher was able to identify other non-verbal indications or events that may have influenced the interpretation of comments.

- Phase 2: generating initial codes.

The second phase of thematic analysis revisited the initial notes made in the first phase, adding to them in a different colour. This process aimed to generate possible codes and categories for data. Examples of these codes were wanting to fit in.

- Phase 3: searching for themes

This phase was split into two sections, the first to identify themes in each stakeholder group (autistic and professional), and the second to highlight any themes occurring

across both groups. When searching for themes, a wider view was taken of the data set to explore underlying or embedded themes, rather than topical based themes. Post it notes were used to mark emergent themes that had been identified, which were then extracted to rank from most important to moderately important. This process also helped to refine themes. Links between themes were explored across the data from each stakeholder group, with a summary of overall themes being described.

The second part of this phase was exploring the themes across all the data obtained. This commenced with mapping the summaries from each stakeholder group and reviewing for similarities and differences. Another strategy used was to utilise the themes from one group and consider how they fit in the data from the other group. Following this process, underlying themes were highlighted, with specific interpretations in each stakeholder group being described.

- Stage 4: review of themes.

Once the first three stages of analysis were completed, a written summary was provided to all stakeholders. This included a summary of each individual workshop, a summary of the themes from their group, and the themes identified across all data. This was presented in advance of the second workshop to allow for comments and corrections to be proposed by stakeholders. Specifically, this was purposeful in ensuring the interpretation of written and verbal contributions was accurate. This shared information formed the start of the second cycle, whereby the summaries of each stakeholder group and overall themes were presented for validation.

The second cycle primarily consisted of co-producing with stakeholders the aims for the workshops. The themes highlighted from the thematic analysis were framed to generate discussion and resulted in an agreement being reached of the purpose of this phase.

- Stage 5: define themes

This stage involved discussions with stakeholders about the topics to be included in the version of the one-page profile. This utilised the themes as motivating factors in decisions made. Having a second facilitator present was beneficial in memoing and collating the themes, whilst also validating previously highlighted codes. Due to it being

a participatory method, the themes were defined through the researcher's interpretation of discussions and reviewing of data collected.

- Stage 6: writing up

In this phase, this stage relates to the final cycle of producing the variation of the one-page profile and the content included in the final report. In doing this, the identified themes were presented, including examples and descriptions given from stakeholders.

### **6.3.9 Ethical considerations**

Ethical approval was sought from the School of Health Sciences Ethics Committee (2020-16813) prior to commencing any recruitment or data collection. A copy of the approval can be found in appendix 35. In addition, the researcher holds an Enhanced DBS certificate (Health and Medical Research – PF).

To meet the requirements of ethical approval, the following documents were produced for stakeholders, which addressed the topics presented below.

- Information sheet (appendices 15-22)
- Consent form (appendices 23-26)
- Debriefing information (appendix 32)

#### **6.3.9.1 Consent**

Consent was obtained through the completion of an online form a month prior to accessing the links for the workshops. This acted as a cooling off period for stakeholders. Surveys online was utilised for this as it was able to generate an individualised link to complete the form, as well as supporting a bilingual document. This form included an opportunity to provide information about their experiences, gaining demographic information to gain an understanding of the stakeholders prior to commencing live data collection. Stakeholders were provided with the Information sheet prior to gaining access to the online link, as well as being available as a reminder when accessing the link prior to the consent declaration.

Informed consent was obtained from the parent (or guardian) for stakeholders under 18, as well as on the day consent from the individual themselves (they could choose not to participate in the discussions or not 'log on' to the online meeting). An information sheet was provided for the parent prior to giving consent, as well as an information sheet suitable for the stakeholder. Should the parent have wishes to participate utilising their own experiences, this was an option after the first phase (their role in the first cycle was supportive in the workshop).

There were variations of information and forms distributed to stakeholders to ensure that the language and information was tailored to that group (see appendices 15-22 for these). The variations were:

- Professional stakeholders.
- Autistic stakeholders 18 and over.
- Autistic stakeholders under 18.
- Parents or guardians consenting on behalf of autistic stakeholder under 18.

#### **6.3.9.2 Right to withdraw**

All stakeholders (parents/guardians as appropriate) were reminded of their right to withdraw at any stage of the process, as well as reminded about withdrawing their data. Consent was obtained from all stakeholders; however, no contact was made with under 18's until parental consent had been obtained. Parents or guardians were not present in workshop unless specifically needed.

#### **6.3.9.3 Deception**

Deception was not required for this phase, as the aims were made clear in the information sheets (see appendices 15-22). In addition, a summary of the material collected through the workshops was given at the subsequent workshop, as well as a copy of the final document after the workshops have been completed sent via email. This also acted as a process of debriefing the stakeholders in how their data, and the findings, would be used going forward.

#### **6.3.9.4 Debriefing**

The final document sent to stakeholders outlined the key themes identified through the workshops and a copy of the document produced. This also reminded stakeholders about how the findings will be used and shared in the future. Similarly, to the information sheet provided at the start, the debriefing information included contact information for the research team should any questions arise. For stakeholders under the age of 18 years, a copy of this was sent to the parent or guardian who provided consent.

#### **6.3.9.5 Protection from harm**

As this phase was conducted virtually, contact information for each stakeholder (and parent/guardian as appropriate) was collected prior to commencing, with an explanation of when this would be used (link to paragraph about confidentiality). This document was shared on OneDrive with the supervision team so that they could access the information in the case of an emergency. If something had arisen to generate some concern, this would have allowed for the researcher to continue the data collection to protect the other stakeholders involved, whilst ensuring the situation is managed.

Within the data collection phase, stakeholders were encouraged to log on to all 'phases', however they will not have to participate verbally. The opportunity to provide reflective comments was given to ensure that all stakeholders were able to contribute their thoughts and experiences. This was to ensure that stakeholders are ok and are not having any difficulties or experiencing distress. Should an individual have not logged on to a session, the researcher would have contacted them by phone to check to see if they are ok. If this were unsuccessful, the supervisory team would have provided support in the steps to take to ensure the stakeholders safety.

The researcher had access to more experienced professionals, who would be available to provide guidance if there were any concerns raised about an individual participating. The nature of the supervisor involvement was defined and explained to the stakeholders established contact. Specifically, this included the need for action if

they considered information shared by a stakeholder to display that they may be at risk to themselves or others. This was also included on the information sheets.

Examples of measures put in place throughout the design to support the stakeholders include:

- Obtaining parental and self-consent for those under 18.
- Completing the first cycle in two strands, one for each group, to support autistic stakeholders feel comfortable, build a rapport with the researcher, and ask any questions without the fear of judgement.
- Another facilitator was present during the second cycle workshops, with this being explained before and during the workshop.
- Enabling comments and thoughts to be shared outside of the 'live' workshop times, in addition to verbal and written contributions during the workshop.

A full risk assessment was completed and approved as part of the ethical review process, including a discussion of both stakeholder and researcher safety (see appendix 35). It was developed in accordance with Bangor University Safeguarding policy, Lone working policy, and the Fieldwork Policy (standards and procedures). Examples of the content in the risk assessment include: the steps to follow should a stakeholder have disclosed something of concern and the communication with supervisors regarding the dates and times of data collection. One supervisor also acted as a facilitator in the second cycle workshops and were provided with a 'crib sheet' of all the information about the workshops, including the tasks that needed to be completed (see appendix 12). They were also given access to the emergency contact information for each stakeholder so contact could be made if a problem emerged, without needing to disrupt the workshop for other stakeholders. The facilitator and researcher 'debriefed' after each workshop, which included a reflection of the discussions, what went well, and any challenges or unexpected outcomes. This reflection was supported by the notes and memoing undertaken by the facilitator and researcher throughout the workshop, which ultimately aided the development of themes.

Inclusion of vulnerable populations was a consideration within this phase. The British Psychological Society's (2014) description of vulnerable populations includes children under sixteen and individuals with learning or communication difficulties. Autism is considered to fall into the category of learning or communication difficulties, which may result in this group of stakeholders being considered vulnerable. The inclusion of this group is supported by the need to include individuals in matters that affect them. In planning the phase, measures were implemented to protect stakeholders under 18, as this was another vulnerability factor. For example, the information sheet and consent forms were simplified, with these being sent after their parent or guardian had consented. The inclusion of stakeholders under 18 was sought as adolescence was the period of development focused upon.

Throughout the teams' discussions, the researcher acted as facilitator, with an additional facilitator present during the second cycle workshops. This acted as a protective factor for the researcher, in addition to acting as a process of validation of themes and products of the workshop. Should breakout rooms have been needed, each would have included a facilitator, with the prompts and topic areas standardised to ensure consistency.

The possibility of harm arising from the participation was balanced by having received consent for all stakeholders (see appendices 23-26). Information sheets were provided, with versions tailored to each stakeholder group (see appendices 15-22). These contained information about right to withdraw, consent, possibility of harm, and other topics within this ethics section. It was considered that there was an extremely low risk of severe psychological harm for stakeholders through participation. Additional measures were put in place for the autistic group to aid in feeling comfortable with the researcher and means of engaging with the project, specifically, the first cycle was conducted separately for the autistic and professional's group. The general topic areas that were being discussed are considered sensitive, however, sensitive topics may present through the direction of the discussions and experiences shared by the stakeholders.

Ground rules were established collaboratively between the researcher and stakeholders within the first cycle, these included expectations of each other, respect,



and the need to respect the privacy of other individual's discussions and not share with others. It was agreed that they would subsequently be referred to as the 'group agreement'. These were recorded and shared with stakeholders prior to the second cycle to allow for additions or amendments to be made. Stakeholders were reminded of these at the start of the subsequent workshops. Box 2 shows the group agreement as decided and agreed by all stakeholders.

<b>Group agreement</b>
<p>If you must leave at any time mid-workshop, let the researcher know. This is to ensure your safety.</p> <p>Confidentiality / privacy – what people say stays within the workshop.</p> <p>Respectful of others – people may have had bad experiences in the past with specific services or processes. These aren't personal.</p> <p>If you want to contribute, use the hand's up function or type in the chat.</p>

*Box 2: The group agreement co-created with stakeholders for online workshops.*

Within this, a method to indicate how to let the researcher know that they are finding the topic distressing or uncomfortable was agreed (turning off their camera and microphone and sending an email). Stakeholders were fully aware of the study aims (through the information sheet, appendices 15-22), as well as the structure of the workshops. However, the risk of psychological harm could not be fully eliminated.

Parental and stakeholder right to withdraw at any time was described on the information sheets (appendices 17 & 18) and the debriefing information (appendix 32) sent at the end of the workshops. A time limit was given upon completion of the workshops, as following that, data would be anonymised and unable to be redacted. This was shared with all stakeholders via the debriefing information sheet. During participation, stakeholders were able to on the day decide not to participate in all, or some aspects of the discussions, without giving a reason. The method of participation was also at the discretion of each stakeholder, verbal communication and written communication was available, as well as follow up comments or feedback via email after the live session had concluded.

Confidentiality was maintained through the anonymisation of data obtained, as well as encouraging stakeholders to not use specific information about comments, for example, not detailing their workplace's name. Stakeholders wishing to use a pseudonym were able to do this, however it was not a requirement. Within the workshops, first names were used, with the ice breaker activities being used for stakeholders to introduce themselves and the name they wished to be used. Transcription was undertaken following each of the workshops by the researcher.

There are however some limits to confidentiality, namely, if the stakeholder disclosed or informed the facilitators that they, or someone else might be in significant danger of harm. In this instance, relevant agencies may need to be informed. Though, where appropriate, this would be discussed and explained with the individual first. The researcher had regular contact with supervisors and was able seek advice about instances that may warrant breaching confidentiality.

Using an online location for the workshops focused upon ensuring that stakeholders could participate without affecting other aspects of their daily activities, for example school, as well as providing easier mechanisms to ensure confidentiality. For autistic stakeholders, this was considered to reduce the potential anxiety and challenges in travel and familiarisation with an unfamiliar environment, and thus more likely to encourage participation. During the evolving pandemic, this was considered to reduce possible exclusion due to shielding, anxiety about travel and localised restrictions. Further, this approach would not have been disrupted should any regulations change once the project had commenced, thus, providing consistency. Guidance was provided about how to access the online tool, troubleshooting measures, and general tips on ensuring stakeholders can participate. This was provided to all stakeholders once consent had been obtained (a copy is provided in appendices 13 & 14).

Data was recorded on an encrypted device, stored on a password protected and encrypted folder, as well as on the University One Drive. All physical data obtained, such as researchers' notes, was stored in a locked cabinet only accessible by the researcher. Data will be fully destroyed after the time suggested by university compliance (five years). Participation included obtaining contact information for the stakeholders in case of emergencies. This was also stored in compliance with GDPR

and was not accessible by anyone except the research team. As data collection utilised software (survey online and teams), after the phase has finished, all information held on these was transferred and saved onto an encrypted folder and deleted from them.

Conducting these workshops and creating data within a controlled setting, Microsoft Teams is considered to limit the ethical issues of misuse or viewing of data. Furthermore, the details of the meeting were provided to stakeholders, with the facilitator acting as gatekeeper to ensure only stakeholders who had confirmed attendance were present. As part of the co-production of the research, stakeholders were involved in discussions around respecting each other, and maintaining confidentiality. Stakeholders had the choice as to if they verbally contribute or use the chat function, whether they have their camera on, as well as the name which they use when connecting. Recordings of the meetings were saved and removed from the team's application to ensure that it could not be accessed by stakeholders.

## 6.4 Findings

### 6.4.1 Stakeholder information

In total, 19 stakeholders contributed to the phases of the research, of which, 10 participated in the autistic group, and 9 within the professional group. Out of the professional group, 2 stakeholders also shared that they were autistic.

<b>Stakeholder identifier</b>	<b>Role title</b>	<b>Brief role description</b>	<b>Additional personal links with autism.</b>
P1	Assistant Educational Psychologist	Assisting the educational psychologists with their case work and research/training within school, conduct 1-1 and group interventions with children and young people to support their needs.	

P2	Director	Director of three user-led equality organisations. All roles include engagement, consultation, and representation.	I am an Autistic Person, I am part of an Autistic and Neurodivergent family, I am the parent and grandparent of autistic girls
P3	Lecturer in Psychology / Autism Researcher	I conduct research on autism, and in particular, how compensatory strategies/camouflaging contributes to late-diagnosed autism and additional mental health problems. I am particularly interested in late/missed diagnosis in autistic females. I also facilitate a Women's Autism group for autistic women.	
P4	Specialist Teaching Assistant	I work with children with ALN in a mainstream primary school. I am a British Sign Language specialist.	I have Asperger's. My son has ASD. I was previously employed as a Learning Support Coordinator at a residential special school for children 9-19 with ASD, LD and challenging behaviour. I run

			a ASD blog, and I have provided community and school training on ASD.
P5	Autism Lead Officer	Strategic lead on matters relating to autism for (Location omitted) Council.	Former chair of governor's special school, autism employment ambassador and current chair of National ASD leads group.
P6	Neurodevelopmental Nurse.	Working as part of a team that assessing children and young people for Autism and ADHD.	I have previously worked in education supporting children with ASD and my daughter is currently being assessed at 30 years old.
P7	Clinical Research Fellow / Forensic Psychiatry Registrar	Academic psychiatric registrar undertaking PhD into co-occurring mental health conditions in autism and providing clinical diagnostic input to (location omitted) Integrated Autism Service.	

P8	National Third Sector Health and Social Care Facilitator	Strategic national lead for health and social care (organisation omitted).	Parent of 2 young autistic adults. One has a severe learning disability and the other diagnosed with Asperger's Syndrome
P9	Advisory teacher for Autism.	Work closely with other professionals to ensure provision for all pupils with Autism is efficiently and appropriately delivered. Provide advice to parents and schools. Deliver training. Lead and contribute to professional learning communities.	Teacher of ASD pupils for 14 years Nephew diagnosed with ASD.

Table 21: Professional stakeholder information.

Stakeholder identifier	Age	Diagnosis (age when diagnosed)	Other diagnoses
A1	19	Not disclosed	Selective mutism, social anxiety disorder, panic disorder.
A2	21	Not specified (20)	Depression, anxiety.
A3	22	Asperger's syndrome (19)	Complex PTSD.
A4	48	Autism (46)	
A5	19	Autism Spectrum Condition (14)	Anxiety
A6	32	Asperger's syndrome (15)	Anxiety, Depression, Hypermobility Spectrum Disorder (HSD / EDS), Connective Tissue

			Disease, partial sight (Myopia & Astigmatism +).
A7	46	High functioning autism spectrum disorder	Dyscalculia
A8	43	ASD (35)	ADHD, C-PTSD, Fibromyalgia, torn & bulging discs, sciatica, TMJD. Dyscalculia, Irlen syndrome.
A9	42	Undiagnosed	
A10	58	Asperger's (56)	PTSD, ADHD, Fibromyalgia, Asthma

*Table 22: Professional stakeholder information.*

The next section will provide a narrative of each phase of the research and the individual workshops within them. Table 23 below situates the stakeholders within each workshop.

	Cycle 1				Cycle 2			Cycle 3		Email
	A slot 1	A slot 2	P slot 1	P slot 2	Slot 1	Slot 2	Slot 3	Slot 1	Slot 2	
A1	✓				✓					✓
A2	✓				✓					✓
A3	✓				✓					
A4	✓				✓					
A5	✓						✓			✓
A6		✓				✓				✓
A7	✓									✓
A8		✓					✓			✓
A9						✓				✓
A10		✓					✓			✓
P1			✓							✓
P2			✓				✓			
P3										✓
P4			✓				✓			
P5				✓			✓			
P6				✓	✓				✓	✓

P7						✓				✓
P8			✓							✓
P9				✓	✓				✓	✓

*Table 23: Stakeholder participation record.*

## 6.4.2 Cycle 1

### 6.4.2.1 Professional workshop narrative

Within cycle 1 workshops, a case study was presented to professionals to encourage discussion of how they would utilise the information on a one-page profile. The case study can be found in section 6.3.6.1

Discussions focused on several prompts (see section 6.3.6.1) to structure the discussion. These included each of the subheadings on the current profile (appendix 10), prompts encouraging reflection of the process of completing the profile and an opportunity for free comments from stakeholders. The sub-headings on the current profile (Welsh Government, 2017) were;

- What do people appreciate about me (like and admire)?
- What is important to me?
- How to support me.

The sub-headings on the current profile (Welsh Government, 2017) and discussion prompts are used to structure the analysis and reflection on this stage. These prompts are used below to provide a structure to the discussions, with quotes being included. Overall, there was a consensus that the information provided was given by a professional and did not include the thoughts and feelings of the autistic person.

Discussions surrounding stakeholders' initial thoughts identified that the profile was aligned with an educational setting and was an outsiders view or observations of the individual. There was a feeling that the information provided in the case study did not clearly identify the implications of the information, with some stakeholders suggesting



that questioning 'so what?' may be a way to encourage reflection when making observations. This is exemplified when describing how:

*"Charlotte on the surface appears to be like many pupils having similar concerns over school and performance. The profile focuses on the negative aspects; where Charlotte has difficulties rather than identifying the positives, celebrate where things are working well and uses them as a basis to support her in areas, she finds more challenging. For Charlotte, a one-page profile should be person-centred and written by her. This profile appears not to be written by her but by the school" (P9 quote).*

#### What do people appreciate about me (like and admire)?

Many stakeholders perceived this as a positive element of the profile as it gave an opportunity for personalised information to be included. Further, discussion arose about the importance of having a starting point for conversation, especially when meeting someone for the first time.

*"The one-page profile fails to identify what others appreciate about Charlotte apart that she is well-behaved, that she has performed well in drama, and she is a perfectionist but that may not necessarily what people like and admire about her" (P6 quote).*

*"The one-page profile focuses on negative aspects and needs to focus on what are the positive for Charlotte and how they can mitigate areas that Charlotte struggles with" (P1 quote).*

*"Should Charlotte see the profile she could be materially affected by the content" (P5 quote).*

*"Positively, her ability to recite Shakespearian text would stand her in good stead should she take up the place at a youth theatre" (P8 quote).*

#### What is important to me?

Stakeholders explained passionately how crucial it was for this section to be fully participatory and a collaborative process, whilst also acknowledging that this would take time. Discussions arose about the types of information that may be included in a profile and the potential for different interpretations of what to put in this section. In the example case study, it was commented that without hearing directly from Charlotte, it would not be known what she felt was important.

*“As this is not written in the first person the author has not fully explored what is important to Charlotte but how she responds to situations” (P8 quote).*

*“The profile identifies that she likes to follow rules but that could be an inhibitor by making her anxious. They identify that her quality of work is important, yet again this also makes her anxious. Charlotte likes to observe before she answers but is worried if she were to get anything wrong” (P7 quote).*

#### How to support me?

Stakeholders described how some individuals may not be aware of how best they need supported, and thus a dialogue with parents or guardians can be beneficial. The case study was viewed as descriptive, providing information such as having teaching assistant support, rather than specific examples of the type of support this is used for.

*“Given this is based upon someone else’s opinion, they have identified that teaching assistant support is helpful but also needs support to interact with her peers but does not say what type of support would be available but that she does have a best friend where this could be useful in exploring wider peer interaction” (P4 quote).*

#### Thoughts of the case study

Overall, the stakeholders viewed the case study was a description of observations made of Charlotte. It was postulated that this did not include a collaboration between all stakeholders, including sharing understandings of the purpose and means of completing the profile. One stakeholder describes how the information did not seem

to fit with the purpose, appearing to be more suited to reports or review of needs in a professional environment.

The case study included information that could have been used within the sections to provide useful strategies and information, for example, using her interest in Shakespeare to act as a conversation starter.

*“This case study could be greatly enhanced had it been written by Charlotte with appropriate support and not by another person. It fails to capture what people like and admire about her which could have a negative impact on her already lack of confidence” (P9 quote).*

*“The Case Study does identify certain characteristics that fit with her diagnosis of Autism but does not fully explore how best to support her with key difficulties” (P7 quote).*

*“It does not look at out of school activities which could support Charlotte to become more confident, feel less anxious and work with her to understand her own and others’ reactions” (P2 quote).*

*“The study does not adequately reflect Charlotte as a person but is defining her by what she finds challenging rather than bringing out positive qualities to help Charlotte to move forward” (P5 quote).*

#### Discussion about the process of completing the profile.

When completing the profile, stakeholders found it difficult to easily put information about Charlotte into the different sections. They reflected on the process and described how they used their own experiences to take the information further into useful statements for the profile. An understanding of completing profiles was inherent, with three regularly completing and reviewing them as part of their professional role. Completing the profile on the information provided was viewed as difficult as there was not much information. In addition, stakeholders described how they wanted to ask questions or explore certain elements further. This reinforces the importance of dialogue when completing the profiles.

Overall, Stakeholders acknowledged that this was useful information to have, though did not feel it was personalized enough to be on a profile and still be a useful tool.

*“Firstly, reiterating the above-mentioned points that the one-page profile is a poor example, if fails to identify her strengths and is negatively framed” (P8 quote).*

*“It is clear that Charlotte did not create her own one-page profile and her seeing it could have a negative impact as it highlights what she finds difficult” (P9 quote).*

*“I do not consider the one-page profile presented as a good example. It fails to give Charlotte a voice. It does not outline what is important to her or for her” (P2 quote).*

*“While it identifies certain traits, I would not advocate using this type of one-page profile” (P7 quote).*

*“One-page profiles work well when children and young people have created their own. This example has clearly been written by a member of the school staff and therefore is not Charlotte’s profile, but one based on another person’s judgement” (P4 quote).*

### **Thematic analysis (stages 1, 2 & 3)**

Following each session, the first three stages of thematic analysis (Braun & Clarke, 2006) were undertaken. This resulted in emergent themes being identified. The discussion below provides a summary of the analysis in these stages.

#### **- Session 1 – professionals (N=4)**

Within this session (95 minutes), four professional stakeholders contributed to discussions, with a general agreement that they had witnessed various levels of perceived success of using one-page profiles. Specifically, comments focused upon difficulties in conveying the level of detail that is needed and the nuanced behaviours and experiences autistic teenage girls may experience. The tool itself was acknowledged as sitting within a wider review process, which was postulated as a reason for it being variable in its implementation. Professionals highlighted that

sensory needs and communication preferences would be beneficial on a profile, though unless someone completing it has a good awareness of the topic, these comments may not be included.

Two of the stakeholders felt that the profile was currently structured to meet the needs of the education provider, rather than the individual. Wider awareness and understanding were described as effective in reinforcing the importance of the profiles being easily identifiable. Suggestions were made of what was considered 'good practice', namely for staff to create a profile for themselves and see if colleagues can identify them from it.

Following the session, notes were made and sent to these professionals for agreement. Within these, three topic areas were identified:

1. People need to know what it is and how to use it.
2. Consider the individual and other key stakeholders to ensure it is reflexive of their needs.
3. Profiles need to be up to date and containing relevant information.

These three topics of implementation, participation and evaluation were taken forward into the second cycle, viewed as emerging themes.

#### - Session 2 – professionals (N=3)

This session (102 minutes) included three professionals, one of whom dropped out of the call at approximately 60 minutes due to internet connection issues.

Initial discussions focused upon the types of needs or behaviours that are identified on the profiles. This included an acknowledgement that quiet individuals can '*go under the radar*' (stakeholder quote). Through discussions of the activity within this workshop, stakeholders acknowledged that sensory considerations were important, as well as considering the various aspects of the day, rather than singularly in the classroom. One stakeholder shared a view that specialist settings are generally better in using and filling in one-page profile, implying that this project would be more

pertinent in mainstream settings. Another branch of this discussion included ways to check that profiles were being constructed based on the individual: 'you should be able to pick up the profile, without name or picture, and know exactly who that person is' (stakeholder quote).

The role of the profile is multi-faceted, providing a summary of an often-large file for an individual, as well as outlining how professionals can best support individuals. The overall view was that autistic individuals should not have to change, but reasonable adjustments should be put in place to reduce anxiety and negative situations. These adjustments often evoked comments about the environment, and the impact of changes or specific features of an environment on an autistic person. The profile was viewed by stakeholders as a proactive document that acknowledged that individuals may vary in their presentation, with triggers included where appropriate.

Overall, this workshop identified three topics:

- The profile as a working document.
- Importance of having a 'good' profile, which is enhanced through training.
- Specific areas need to be addressed in the profile, sensory considerations, environment, communication, and triggers.

These three topics of procedure, implementation and categorization were taken forward to the second cycle, viewed as emergent themes.

#### **6.4.2.2 Autistic group narrative**

Within cycle 1 workshops, autistic stakeholders were encouraged to use their own experiences to describe how they may complete their own one-page profile. Specifically, this included the type of information they would want to be included. The prompts used were the same as the professional group to maintain consistency (see section 6.3.6.1) and the three sub-headings on the one-page profile.

Overall, this demonstrated a dislike of the 'like and admire' section, as well as finding it challenging to reflect upon what they are good at. Some stakeholders were able to identify things to put in this section, though these were generic statements, such as 'quiet', 'follows the rules' and 'I find work easy'. Others felt that this section would be problematic for them to complete, even with the support with someone they trusted. There was the concern expressed that if they were unable to complete the section, someone else would make assumptions and complete this on their behalf. When discussing how the autistic stakeholders would complete the 'how to support me' section, it was discussed how in documents they had experienced, this often-included generic information or links to other sources.

*'We have these online learning agreements for my tutors, so they know what I need, but they are just generic bits of information and a link to a website with how to support autistic students...'* (A1).

The discussions included anecdotal accounts of support the stakeholders had received in the past, including the perceived success of these. Overall, there was an underlying consensus that support had room for improvement, specifically in mainstream educational settings. The descriptions of support experienced varied, including practical support, for example, learning assistants in classes, to psychological support, for example, key workers to prompt coping strategies when they were getting overwhelmed. One stakeholder described how they were not aware the type of support they could receive, or what they could ask for, which they felt would have been useful to know. This was validated by the other stakeholders and expanded to include the one-page profile more generally, as without knowing the scope, it would be difficult to complete. Upon reflection, there was a consensus in both sessions that this was not be best use of space on the document and did not seem to have any benefit, rather potential negatives. Negatives described included reinforcing stereotypes of autism, creating an expectation upon oneself to do those things all the time, and the worry these would be used to de-validate difficult and challenging experiences.

As completing this profile was challenging for stakeholders, the researcher moved the discussion on to general thoughts about their experiences, what good support looks like and the type of information they would like others to be aware of.

Through both sessions with autistic stakeholders, the desire to avoid confrontation was frequently discussed. This included the perception that people who do not understand how stimming can be beneficial in reducing anxiety often told them to stop, with specific examples of being reprimanded through detentions by 'disobeying a teacher or an instruction' (Stakeholder quote, A4). In including such information on the one-page profile was described as 'giving permission to fidget or calm myself down' (Stakeholder quote, A8). None of the autistic stakeholders had a one-page profile or similar document during their period of adolescence, however they stated that such a document would have given them the reassurance and 'permission' that they could be themselves, acting as an agreement that they can stim or use coping strategies without negative consequences. Two stakeholders generated a conceptual discussion surrounding the views of autistic people and professional stakeholders, reinforcing the importance that the purpose and bounds of the tool are shared by all parties for it to be affected. This was validated by others in the workshop who described the 'tokenism' (A7 stakeholder quote) of the tool if it was not 'embedded in wider understanding and acceptance' (A10 stakeholder quote).

Within the second workshop for this group, validation was discussed in detail. This included the role of the profile as validating the individual's needs. Additionally, narrative accounts of negative educational experiences were situated as examples where autistic people's experiences of the world, or challenges, were de-validated.

*'Having just got my diagnosis, I was trying to get my head around it all. The last thing I needed was people dismissing it saying I didn't look autistic, or that it was only mild. They (teachers) frequently said I was exaggerating or overreacting which made me question myself as I didn't know what to believe, after all they were teachers and me just a child'* (A5 stakeholder quote).



## **Thematic analysis (stages 1, 2 & 3)**

### **Session 3 – autistic (N=6)**

This session (118 minutes) included six autistic stakeholders. Three of these stakeholders were enrolled in a university degree and were within the age range for the ALN code of practice (0-25years old). In reviewing the current format of the profile, a mutual agreement was gained surrounding the ‘what people like and admire section’, describing it as a *‘vague and abstract concept which makes me uncomfortable to think about and read’* (stakeholder quote).

Through the discussions, stakeholders identified that a lot of the topics and information included was personal preference, and therefore the individual should be consulted about any decisions made. Including strategies on the profile was considered beneficial, providing they were personalised and agreed upon by the individual. Another role of these was described as giving the autistic person *‘permission’* (quote) to use them without the fear of retribution. This fear of being told off leading to shouting and confrontation elicited a lengthy discussion, in which all stakeholders contributed their own experiences of this. Similarly, to previous workshops, identifying specific sensory needs was considered important, though it was framed in a way as justifying the coping strategies employed, such as wearing headphones. Another element to the profile was the possibility for it to challenge assumptions and stigma that they had experienced. For example, identifying stimming as a coping strategy rather than someone not listening or misbehaving.

Two stakeholders identified the profile was something that they had come across prior to taking part in these workshops. It was agreed that completing the profile should be done as a collaborative process, allowing the autistic person to complete it in a chosen place, likely to be at home with a *‘safe person’*. In identifying the role of the profile, stakeholders viewed it to be a proactive document and retrospectively considered to have prevented or reduced the severity of challenges experienced.

Overall, this workshop identified several topics.

- The current topic areas are not appropriate for the autistic person but focus on professionals.
- Creating a profile should be a collaborative process which is open to review at any time.
- The document needs to be personalised so that it can have the greatest benefit.
- Subheadings should include signs of starting to struggle, as well as known triggers.

The topics of construction, procedure, personalisation, and categorisation were taken forward to the second cycle, viewed as emergent themes.

#### **Session 4 – autistic (N=3)**

This session (150 minutes) involved three autistic stakeholders, one of whom is in full-time postgraduate education.

Drawing on personal experiences, stakeholders described the importance a holistic view that accounts for possible comorbidities in the profile. It was also acknowledged that these comorbidities may require a specific section within the profile. Utilising one page for the profile was considered restrictive, it was considered better to take more space and present the information clearly, than omit information or cram it onto the one page. This discussion involved a discussion of potential topic areas to guide the construction of the profile; sensory, communication, environment, coping strategies, safe space and warning signs or triggers. After seeking clarity, these topics were viewed as prompts to aid the development of the profile, with flexibility to use as appropriate.

Stakeholders acknowledged the sentiment behind including the like and admire section on the profile, however, it was viewed as focusing on others' needs not the autistic individual. When seeking clarity, a stakeholder explained that having this section could *'lead to mental health complications...there is a pressure to conform and be like that all the time – in turn encouraging masking'* (stakeholder quote).

When constructing the profile, discussions focused upon building a rapport with the autistic person and establishing trust before commencing on the profile. One stakeholder described that some individuals may require some support and prompting when responding to filling the profile in. Importance was placed on this being considered on a case-by-case basis, as well as identifying caution that it does not overpower or ignore the autistic persons views.

Overall, the profile, if completed and embedded appropriately, was viewed as effective and valuable. Stakeholders reinforced their preference for blunt statements and information rather than vague and abstract statements.

Three topics were identified to be taken forward as emergent themes:

- Profiles need to be tailored to an individuals' needs.
- These profiles need to be a collaborative process.
- The like and admire section is not a good use of space and focuses on the needs of professionals.

#### **6.4.2.3 Development of emerging themes across both stakeholder groups (thematic analysis stage 4)**

Through the analysis of professional and autistic stakeholder groups, three overriding themes were identified. These were; the tool needs to be specific; titles and sections should reflect the individual's needs and it needs to be used, reviewed, and updated. These three themes were presented to the stakeholders in the second cycle for validation. The remaining phases of the research were designed as collaborative discussions to produce a report, reflecting upon the elements that make a good profile and wider topics and concepts that underpin these in practice. In addition, subtitles and elements for the profile would be defined and explained through the document.

- The tool needs to be specific

The tool needs to be specific and tailored for everyone's needs, for example, signs someone is struggling, triggers and sensory considerations. Clearly outlining a safe space and person is important for both individuals and professionals. Conceptualised process of creating a profile as proactive. The second phase aimed to further develop this theme and identify the visual design of an adapted tool.

- Titles and sections should reflect the individual's needs

Titles and sections included on the profile should reflect the needs of the individual, though some standardisation was desirable. Overall, the titles should prompt information that is helpful, with a holistic view encompassing the social model of disability. The second cycle aimed to generate these titles and the topic areas that needed defining. These would be framed within a document co-produced with stakeholders.

- It needs to be used, reviewed, and updated.

The tool needs to be used, reviewed, and updated as an ongoing process, thus it is a working document. Whilst currently used for reviews (e.g., Individual Development Plans), stakeholders agreed there were benefits for a similar tool in day-to-day life across education health and social care settings. Guidance information should be clear and to the point and such a tool should be embedded within wider training and awareness of equality, inclusion, and participation. The second phase focused upon creating a tool that met these needs.

### **6.4.3 Cycle 2**

In this cycle, sessions 2 and 3 had an additional moderator present who took notes that were used to help define themes.

#### **6.4.3.1 Session 1 – 2 professional stakeholders**

Following the summaries of the first cycle being sent to stakeholders, a verbal agreement was obtained to validate the emerging themes drawn from them. In addition, stakeholders discussed the level of flexibility in the design of one-page profiles. Both acknowledged the reasons why full flexibility is desirable, though, from

their professional positions felt that there needed to be '*some structure so there is some consistency*' (Stakeholder quote). The use of specific topic prompts in key areas was discussed, with stakeholders favouring this approach.

One stakeholder (P6) mentioned a document available to them locally to support in conducting assessments, this included several topic areas potentially relevant to profiles:

*'Eye contact: appropriate/fleeting/comfortable giving it (acknowledge learnt behaviour).*

*Speech and language: understanding/expression/subtle language difference.*

*Social cues: understanding/turn taking/awkward/misunderstand/literal thinking/ask for help/facial expressions.*

*Anxiety; change/routine/emotions/behaviour.*

*Friendships*

*Imagination*

*Interests' (extracted from document provided by a stakeholder).*

These topics were acknowledged as a good starting point, though stakeholders acknowledged other key areas to be included, namely sensory issues, triggers, coping strategies and camouflaging. The researcher provided a summary of the discussion, during which these themes were agreed upon. Stakeholders described that having an appropriate tool needed to go alongside a wider culture of awareness, training, and development. Drawing on personal experiences of training, learning through doing was viewed as the best practice.

Throughout this workshop, several wider topics were discussed, including participation and collaboration, presentation of difficulties, inclusion, equality, and diversity. Overall, a large amount of discourse was elicited through this workshop, validating previously emerging themes. The one-page profile was positioned as a supportive process which has a great potential to benefit individuals if it is personalised to the individual.

#### **6.4.3.2 Session 2 – 1 professional stakeholder and 6 autistic stakeholders**

After presenting the summary of the first cycle, autistic stakeholders reinforced concern over professionals' views being more favourable. Suggestions were also discussed of how to ensure the profile is a working document, including an anecdote about a cleaning checklist in public toilet facilities. This was not viewed as sufficient, so further ideas emerged including mandatory reviewing and reading of the profiles with the ability to ask questions. Ensuring this is a collaborative process was agreed as important – the perception of hierarchy and positioning of expertise was identified through these discussions.

Following on from this discussion, the summaries provided were agreed. Prompts by the researcher subsequently focused on tailoring the tool and seeking clarity on the specific topic areas identified through the first phase. This provoked discussions around the '*core areas*' or '*fundamentals*' that need to be understood. Such areas included: meltdown / overwhelm, anxiety, executive functioning and identifying a safe space. Utilising a rights-based approach was discussed through one of the stakeholder's experiences in a legal environment. Within this, explicit permission to share the profile and for changes to be made to it were supported.

Through discussions, clear topic areas were identified. In addition, collating these alongside the wider contextual topic areas was suggested as a possible output from this research. As this followed the previous workshop in this cycle, the topic areas identified there were used to guide discussions (see above).

#### **6.4.3.3 Session 3 – 2 professional stakeholders (also autistic) and 1 autistic stakeholder**

The summary of the first cycle was shared with the stakeholders, with discussions following further reinforcing and validating the identified themes. Specifically, the flexibility of the topics of information included in the profile. Language such as

'balanced' and 'clarity' were used when describing the types of information used, for example, balancing the amount of information and making sure that it is easily understood. When discussing the length of the document, all stakeholders supported the length of the document not being restricted. The difference between length of document and usefulness of the information was discussed, with a consensus being agreed that a profile over two pages with clear information was more desirable than one page with crammed information or sections omitted.

Discussions of the length facilitated a natural shift to discussing the structure of the profile and the subheadings used. One stakeholder described those categories would be a useful way of making the information clear, with the ability to use those important for an individual. This also expanded upon the vagueness of the 'how you can support me' statement, with suggestions that this is embedded within all sections, considering the role of the environment and other factors on what support is needed.

Through discussion, it emerged that in their positions as parents, understanding the profile and what information could be included was a barrier. Specifically, a lack of guidance and background to the profile and the role it has. This was summarised through descriptions of *'needing training on how to use the document as well as framing the document differently and awareness training to interpret and implement what comes from discussions – otherwise reliant on specialist (who are often absent or difficult to contact)'* (Quote, P4).

Completing the profile was described as pointless if it is not viewed, understood, and reviewed. Through the facilitator's narrative of cleaning checklists in public facilities, stakeholders described their thoughts of how this could be achieved. Within this discussion, stakeholders discussed the perceived negatives of this simple checklist approach, as it was perceived as a tokenistic approach that would be difficult to monitor if the reader had understood and engaged with the profile. Stakeholder A10 summarised this discussion, describing how:

*‘There needs to be more than a sign off process...profile reviewed every half-term...a collaborative reading of it, e.g., family lead, edit with family, staff meeting and read through and agree and that everyone understood and then engage with individual – as young person- a core group meeting...’.*

This was subsequently validated through agreement with the other stakeholders present within the workshop.

Implementing the profile drew on the role of technology to embed these profiles in practice. Specifically, the use of QR codes to store the profile information was discussed, allowing for them to be updated and with the ‘live’ version being accessible.

The cultural shift was significant in this workshop, specifically in descriptions of the multiple layers of using the profile in society, specifically embedding this at all levels from governance, school leaders and professionals. See figure 10 to highlight cultural shift within the identified themes.

#### **6.4.4 Topic areas highlighted to be included on ‘one-page profile’**

Through the first two cycles of workshops, several topics and terms were highlighted as being important, either as topics to be included on the one-page profile, or wider understandings and practices to make best use of the tool. Through memoing, these were listed and defined to provide a structure to the document. The emerging themes from the first cycle were all included in the document, though, through the second cycle, it emerged that knowledge and understanding varied, therefore, prompting questions and information about why the topics are important were deemed important.

*“Some people have been brilliant and understand, but some people don’t so it has to be crystal clear. In my view, the document should assume the reader has no knowledge or prior experience” (A3 quote).*



In positioning the one-page profile, it was viewed as important to ensure a clear understanding of its purpose and background, therefore, a list of topics and definitions to be included were identified and agreed with stakeholders. For example, concepts of inclusion, definitions of stimming and the importance of reflexivity (see box 3 for a list of all the topics included). These discussions also highlighted topic areas that individuals may wish to include on their profile to ensure a mutual understanding among all stakeholders with access to the profile. For example, highlighting a safe space, sensory preferences, and signs that they may be starting to struggle (for a full list see box 4).

The target reader for the document produced was discussed through the second cycle, with benefits identified for a range of individuals. Specifically, an autistic stakeholder described how *'when I was asked to do one for my son, I had no idea what one was, and the school just expected me to do it'*. This was reinforced by professionals, as there were examples described where teachers and parents had differing understandings of the document, with the process not being clear. As the study focuses upon adolescent females, it was discussed that it may be useful for them to access information about the profile, to include them in the process fully. The term *'alien concept'* was described in several instances; when describing what others like about me, what needs to go on a profile, so providing information and prompts was considered useful. The topics creating the standardisation to the tool (preferred by the professional group) emerged through discussions, with it being viewed as important to categorise information and present it in a logical order.

*'There is no point you are knowing how to best support me if you don't know what name I like to be called by...'* (A1 quote).

*'It is important that the foundations are set when building a relationship with an autistic person, for example, knowing their specific triggers and warning signs'* (P2 quote).

In deciding the topics to be included in the document and profile, the overall purpose of reducing unnecessary anxiety, facilitating proactive support, and preventing extreme negative experiences was desirable.

*‘If there was something like this when I was in school, I think it would have really helped people to understand me, rather than just making assumptions because I’m autistic’ (A2 quote).*

One page profile purpose

ALN Transformation Programme

Concepts – social and cultural

United Nations Convention on the Rights of Persons with Disabilities (CRPD)

Inclusion, equality, and diversity.

Awareness.

Participation and collaboration.

Concepts – contextual

Spectrum

Presentation

Masking / camouflaging

Stimming

Anxiety

‘Translator’.

Guidance

Reflexivity

Presentation

Implementation

Innovation

Embedding

Training

Topic areas and prompts

*Box 3: A list of topics identified to be included in the document.*

## Overview

- Photo (optional)
- Name (known as)
- Pronouns (optional)
- Diagnoses (optional)
- Language
- Safe space
- Safe / trusted person
- Any medical alerts
- Things I am good at / facts about me
- Other key information

## Communication

- Preferences
- Eye contact
- Instructions
- Processing

## Anxiety / stressors

- Triggers
- Effect on communication
- Signs
- Coping strategies
- How to reduce
- Changes

## Environment

- Sensory needs
- Free time
- Coping strategies
- Physical needs
- Transitions

## Community

- Friendships / interactions with peers
- Interests
- Relevant adjustments

## Care needs

Any support needed or anything relevant.

## Sensory

Impact of sensory needs

Touch

Relevant adjustments

Movement

Body position

Looking

Hearing

Smell

Taste

## Meltdown / shutdown

Signs starting to struggle.

What to do.

What not to do.

Signs of meltdown behaviours / non-verbal communications.

Specific signs.

## Other

Anything that the individual wants to know, may focus upon previous misconceptions or things they want people to know.

Links to other documents.

## Permissions

Permission for others to communicate on behalf.

'Translator' use.

## Review

Date of latest review.

Date of next review (at latest).

*Box 4: A list of headings and sub-headings on the profile*

### **6.4.5 Phase 3 - feedback**

#### **6.4.5.1 Session 1 feedback – 1 professional stakeholder and 1 autistic stakeholder**

This session involved reviewing the draft document sent, specifically focusing upon the topics to be included. All topic areas and subheadings were validated and agreed upon, with specific comments supporting including visual examples of how the profile would look. In specific areas (topic of participation), it was suggested that the language be reviewed to ensure it is as clear as possible.

#### **6.4.5.2 Final document - agreed and sent via debriefing.**

The document coproduced through the workshops is not a finding per se, though the topics included in the report and the underlying concepts contributed to the analysis (see appendices 33 & 34 to view the full document). Stakeholders were sent a copy of the draft document with information of ways to provide feedback. A date was given four weeks in advance for when all feedback needed to be received. Once this date had passed, comments were incorporated in the document, with the final document therefore being shared along with the debriefing information. When receiving feedback, changes were categorised into two types. The first, content alteration and second non-content alteration. Content alteration was conceptualised as changes that would alter the sentiment of the discourse, alter the position, or affect the understanding of a specific section. Proposed alterations were shared with stakeholders and an agreement was reached through discussion. An example of this feedback was including legislative frameworks to reinforce that inclusion and adjustments are mandated and monitored, such as the Equality Act. Non-content alterations included grammatical changes and sentence structure amendments. These were changed without consulting all stakeholders but were highlighted as changes in the document for agreement.

This process was not considered analytical, however, some emerging similarities emerged. These include the feedback from professional stakeholders primarily being categorised under non-contextual changes, with autistic stakeholders commenting on

content alteration and the order topics were places in the document. In total, two changes were made as a result of content altering feedback, and ten changes were made following non-content altering feedback. Overall, feedback that suggested changes came from professional stakeholders, with autistic stakeholders frequently commenting that they were happy with the document. Upon reflection, these differences between groups may be a result of the burden of reading a document and providing feedback, as such, it is suggested that in future stakeholders are given a wider range of opportunities and methods to provide feedback. Box 5 provides excerpts from two written feedback emails.

### **Written feedback received from further stakeholders.**

*I have read through the draft, and I love it! I didn't pick up on anything I would like to change. I had a look through the layout of the 1pp and it looks really clear and easy to use - I hope these can be used in education/work settings in the future as I think they will make a huge difference. Thank you so much for choosing to do this work, it's super appreciated!! 😊 (A2 quote)*

*Not much to comment other than to say it looks great and seems to cover what was discussed at the workshops...It's very in depth across all the sections, and I guess my one concern would be whether all the information would end up being used. A lot of the time this information is a 1-page crib sheet given to temporary/cover staff who may not have time to read it all. I think Version 3 would probably get used the most because of that. Great to see how this has developed. (P7 quote)*

*Box 5: Examples of stakeholder feedback.*

### **6.4.6 Synthesis of key themes**

Through the workshops, the direction of the data produced altered in response to the discussions with stakeholders. Specifically, this involved interpreting the initial discussions in the first cycle to identify that creating a new version of the profile would be the best use of the workshops. This was subsequently validated by stakeholders by sharing interpretations via email and presenting them at the start of the second workshop. This allowed for stakeholders to comment on the interpretations and

ultimately validate them through agreement (this was a mixture of verbal and written agreement). Producing the report presented an opportunity to take the experiences and expertise of all stakeholders and use them to form a product. This was described by stakeholders as a proactive use of the time, rather than becoming a tokenistic approach that *'gets information but does nothing with it'* (Stakeholder quote). Through the discussions at all cycles of the workshops resulted in several themes and understandings to be identified, these were presented to stakeholders and validated. These themes were described as the underlying factors that influence the success and appropriateness of any profiles used, as well as all being related and working alongside each other.

The three themes are presented in figure 10 and include:

1. The need to balance the needs of professionals against the importance of personalising the tool, underpinned by a collaborative process.
2. The profile fitting into a wider cultural shift, positioning the autistic person in the centre.
3. The tool being proactive not reactive and viewed as a living document.

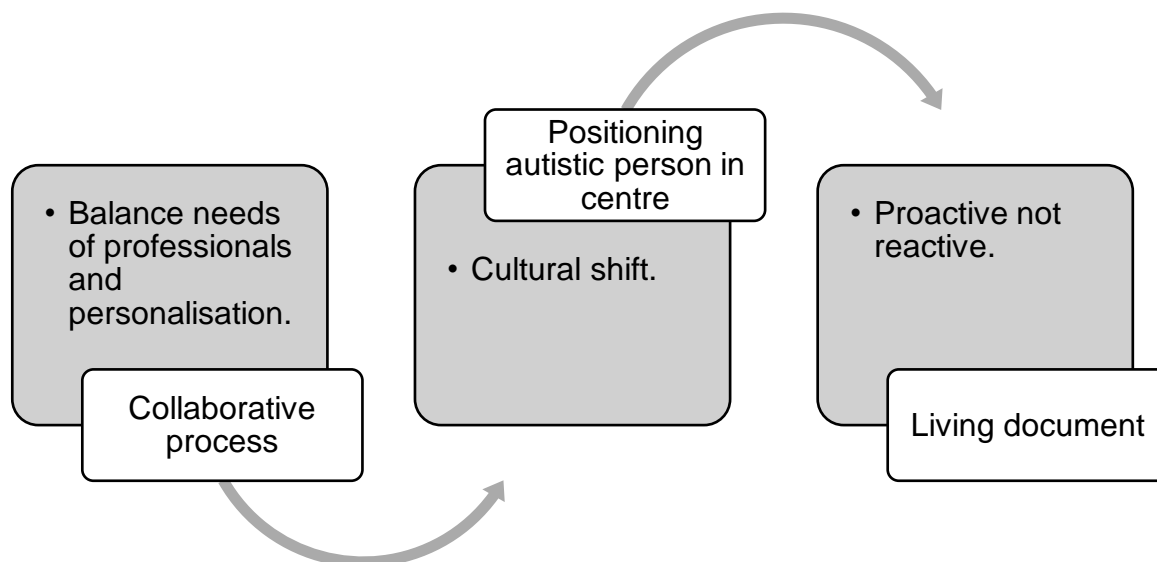


Figure 10: The key themes identified and their relationship to each other.

#### 6.4.6.1 Theme 1: Balancing the needs of professionals and personalisation through a collaborative process

Firstly, the collaborative and participatory nature of the profile was identified as a clear theme. This also acknowledged the importance of balancing the needs of different stakeholders in deciding the content to be included, without impacting the level of personalisation of the profile. The needs of professionals were acknowledged when including an element of standardisation in the topic areas and structure of the profile. This theme included the clarification of the elements of participation, where five sub-titles were suggested, including: inform, consult, involve, collaborate, and empower. Each element was defined along with suggestions of how they should be utilised. These were presented to stakeholders to be amended and subsequently agreed to be included in the final report. Table 24 displays a summary of these descriptions and recommendations.

	Definition and recommendations
Inform	Information should be provided to all relevant stakeholders, including autistic people, in a format which is accessible. Information should be balanced and objective, to assist in deciding based on the content. Clear dates or times where updates are to be expected should be shared, as well as updates with any change or development. We recommend that informing stakeholders needs to be accompanied by plenty of time for a decision to be made, as well as doing so in an environment of their choice (e.g., at home).
Consult	All stakeholders should be consulted and valued equally, though this may be achieved through different methods of engagement. Consultation should be embedded, providing regular opportunities to feedback, rather than at a single timepoint. Any actions taken or changes made following consultations should be made accessible and clear to all involved. Further, these records should include identification of the reason the change was made, and information about the consultation process.
Involve	Stakeholders should be involved in all stages of the consultation and the implementation of findings as appropriate. Involvement should



	continue to embed an understanding of all views being equal and valid. How stakeholders are involved should be reflexive to their needs. Following contributions, interpretations, and reporting of these should be shared with stakeholders for agreement.
Collaborate	To partner with all stakeholders in all aspects of decision making. This should also take account of the preferences individuals have, and where possible, these should be prioritised.
Empower	This involves empowering individuals to get involved with the processes involved with participation and being able to freely express views without fear of dismissal. Embedding this within society will benefit the other processes discussed. To fully empower autistic people, they should be positioned as experts in their own lives.

*Table 24: Stages to participation agreed with stakeholders.*

#### **6.4.6.2 Theme 2: Positioning autistic person in the centre and a cultural shift**

Second, positioning autistic people in the middle of all things that concern them was identified as crucial. This included ensuring that the methods of completing and reviewing their profile is accessible allowing for contribution. This is underpinned by a cultural shift, encompassing going beyond awareness to acceptance and moving away from deficit driven understandings of disability.

The cultural shift identified by the stakeholders encompassed key themes and definitions that were included in the report. The phrase was agreed to reflect the multi-faceted range of concepts, including legislation, that were needed for the profile to be most beneficial. For example, embedding awareness and acceptance for neurodiversity will reduce any possible stigma associated with having a one-page profile. When describing awareness, stakeholders strongly reinforced the importance of autistic people leading from the front, as experts in their own lives. When considering embedding awareness within professional stakeholders, it was described as an ongoing process that needed to be reviewed and adapted.

This understanding demonstrates the position of this work in a much larger context. Specifically, this version of the one-page profile is a single tool in a multi-disciplinary field, though it contains the worldview and position that they idealised.

#### **6.4.6.3 Theme 3: Proactive not reactive and a living document**

The final theme is that a one-page profile should be viewed and treated as a living document, that is able to be refined continually, with scheduled reviews and the ability for any stakeholder to request it be revisited at any time. This is underpinned by the nature of the document as being proactive, putting things in place to support individuals and provide information should a difficult situation occur, rather than something created in reaction to an event, created out of necessity.

As shown in figure 10, each theme is underpinned by wider concepts and developments. The theme of collaboration is linked with balancing the needs of the different stakeholders, specifically within this phase, the professional group, and the autistic group. The theme of positioning autistic people in the centre is supported by a wider cultural shift in understandings and positioning of disabled people. The cultural shift is viewed as a scaffolding structure to ensuring autistic people remain at the centre of decisions. The final theme of the one-page profile being a living document reflects the changing environment and positions autistic people have throughout their development. Specifically, this reflects the proactive motivations for completing a one-page profile, rather than reacting to events and experiences in a reactive way. Through discussions, these experiences were often negative, described by autistic people as meltdowns or when they are overwhelmed.

The figure represents the three themes and underlying concepts as interlinking elements that contribute to the one-page profile being used successfully. Through discussions with stakeholders and analysis of discussions, the order of these was identified as each building on the prior, but all with equal importance. In addition to being identified as themes, these concepts were considered as the values and principles individuals should adopt when completing or reviewing a profile.

## **6.5 Discussion**

This section will reflect upon the findings of this phase, drawing meaning to themes as well as reflecting upon the process of facilitating the workshops and creating the report.

### **6.5.1 Positioning**

Both groups of stakeholders drew on their own position when contributing to workshops, with personal experiences directing these positions. In discussions of positioning theory, Harré, Moghaddam, Cairnie, Rothbart and Sabat (2009) describe the distribution of rights and duties within interpersonal encounters. Applied to discussions undertaken through the workshops, rights were primarily ascribed by autistic people, with professionals being duty bound to ensure these rights were met. Drawing on the experiences of both groups increased the ability for results to translate into real life experiences. In Long (2017), this is described as having the potential to overcome difficulties in translating information into practice.

Through co-production, each stakeholders' experiences and positions will have influenced the trajectory and decisions made about how the workshops were structured and the overall aims. Additionally, their experiences provided examples of where the profile may have been useful and the information that would have been included.

Participation in this phase was voluntary and there was no financial incentive for stakeholders to take part. As a result, it is likely that stakeholders had other motivations to take part and contribute, for example, an interest or investment in the topic area. This may have been a benefit in building the rapport between actors, specifically a reassurance to autistic stakeholders that the motivations to being involved were similar. Through the ground rules established, the autistic group expressed the desire to include a statement surrounding any personal experiences should not be taken as a criticism of them, rather they were voicing their lived experiences. The coproduction

of ground rules mirrors the method utilised by Stark *et al.*, (2020), specifically in creating a supportive environment where stakeholders felt safe. In further reflection of Stark *et al.*'s (2020) paper, coproduction is described as the highest level of meaningful involvement. Figure 11 outlines the different roles of autistic adults in research (Stark *et al.*, 2020, p.4) and reinforces this research being categories as co-produced.

When co-producing the aims of the workshops with stakeholders there was the potential for embedded knowledge hierarchies to limit the participation of the autistic group. However, through the workshops, this was actively challenged by professionals and autistic people, with specific discussions about who is the expert where a consensus was drawn that actors have expertise and a dialogue between these is best practice. This outcome supports Durose *et al.*'s., (2012) description of co-production as challenging hierarchies between the perceived expert and layperson. Conceptually, the workshops were able to create a space involving stakeholders from a range of backgrounds, or as Pohl *et al.*, (2010, p.268) from different 'sides of the boundary'.

### **6.5.2 Group dynamic and contributions**

All autistic stakeholders contributed through describing their own experiences, which included the researcher. The nature of these workshops utilised social support and shared experiences to build a rapport, specifically through the first cycle. Experiences and questions provided by both stakeholder groups were viewed with respect, thus, positively reinforcing those sharing, which encouraged others to do so. As judgement featured in several retrospective accounts of disclosing their diagnosis, the autistic stakeholders sought support from each other as peers when discussing the second and third cycles of the phase. Specifically, a discussion in one of the workshops identified how individuals felt they were a collective and thus, would support each other, through the shared purpose and mutual understanding established previously. This was beneficial in ensuring the atmosphere was warm and relaxed when both groups met for the first time. The professionals also appeared to open-up as the stages progressed, with comments being made of not wanting to ask a silly question or look that they did not know something. Interestingly, the professional group were seeking the insight of the autistic stakeholders, something which aided the rapport that built up

between the two groups. As the purpose of the phase was shared with all stakeholders before beginning, the shared purpose was established before communication commenced.

Stakeholders' views of the benefit of collaboration and an open dialogue are supported by scholars, including Azad *et al.*, (2016), Sheridan *et al.*, (2012) and Roberts and Simpson, (2016), who describe these as developmentally beneficial for all children and young people. Having this in place in education settings is described as mutually supportive for parents and teachers (Epstein, 2018), thus reducing potential conflict and dissatisfaction between both parties (Wood & Oliver, 2011)

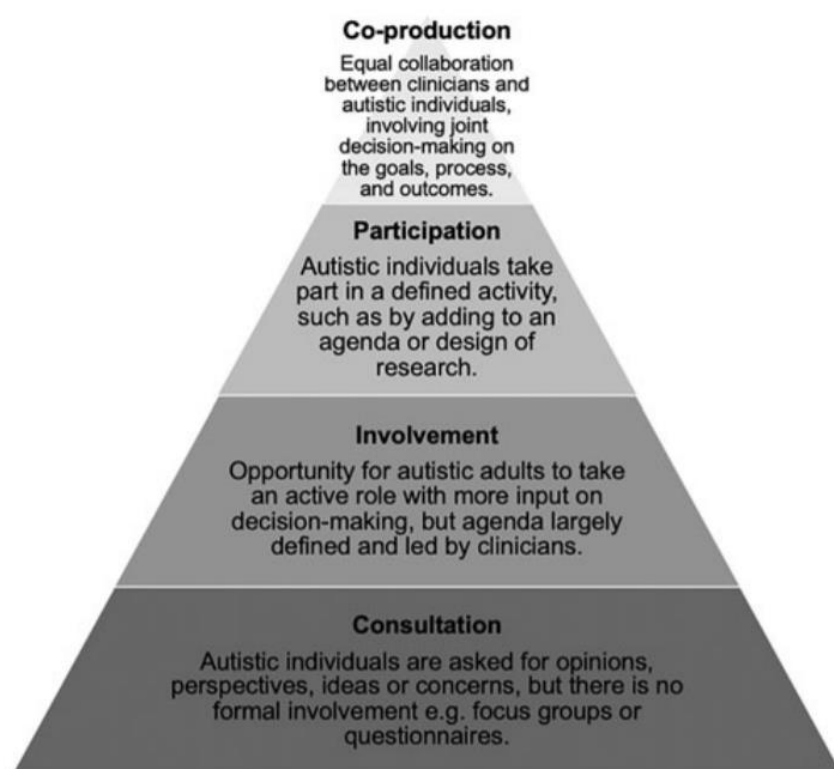


Figure 11: Stages of involvement described by Stark *et al.*, (2020).

Encouraging the opinions of all stakeholders was considered important, with examples provided highlighting instances where this was not the case. Specifically, autistic stakeholders described their opinions being dismissed and downplayed. Both autistic and professional stakeholder groups acknowledged the potential for hierarchy to

influence decisions made as well as highlighting that each stakeholders contribution when constructing a profile such as this provide an insight into the young person's experiences, and as such should be valued.

These discussions resonate with Kurth, Love and Pirtle (2020), who describe the different beliefs that families and professionals may hold, specifically in identifying the priority. As a result, there is a potential for conflict, distracting from the individual's needs, making the system and structures disjointed and unable to maintain cohesive support (Vassallo, Dallos & Stancer, 2020).

### **6.5.3 Professional stakeholders who disclosed being autistic**

As described earlier in this chapter, two of the professional stakeholders disclosed that they also were autistic. This presents a unique opportunity to explore positioning as members of the professional and autistic groups. In discussions with these stakeholders, they considered that being autistic was a positive attribute within their professional lives. However, they also identified challenges where reasonable adjustments were not made in their working lives. The impact of stakeholders falling within both groups meant that a discussion was undertaken to identify their preferred group to be identified in. As these stakeholders had a broad range of experiences in various professional roles it was viewed to be the more appropriate grouping. However, this may have influenced how they decided to share information in the workshops, specifically when drawing upon their own experiences. In addition, through the dialogue both disclosed to other stakeholders that they were autistic, which may have impacted upon the way in which other professional stakeholders contributed within the first cycle.

The inclusion of stakeholders with these two positions was considered to reflect the multiple positions people can inhabit in society. For autistic stakeholders, being among other autistic people who are leading successful professional lives acted as a motivational influence. Retrospectively it would have been useful to obtain a larger sample of stakeholders who inhabit multiple roles to explore the impact of this further.

Both professionals who identified as autistic demonstrated a deep insight into the benefits of one-page profiles and the need to use them to their potential.

#### **6.5.4 Identity and cultural shift**

Throughout the workshops, identity was frequently discussed, for example in diagnoses and pronoun usage. The inclusion of these on the profile was agreed as optional, with autistic stakeholders each describing their own preferences and use of labelling when considering identity. Mirroring discussions in Mogensen and Mason (2015), identifying as autistic for some was viewed as liberating and self-assuring. In comparison, labels were discussed as being limiting when included at the request of professionals or parents. Similarly, Hodge (2005) discusses the potential for labelling on information documents such as profiles to limit individuals in developing their own identity as well as encouraging deficit driven understandings to be shared (Mogensen & Mason, 2015). Deciding if identity markers should be done on an individual basis, a view that embraces neurodiversity and difference rather than deficit (Connors & Stalker, 2007).

Embedded within the cultural shift identified through the workshops is the use of language. Vivanti (2019) describes how identity-first language is an element of the cultural shift, with it counteracting the separation of autism from an individual. Advocacy groups have been discussed in driving forward this shift, with examples of this being visible through increasingly open access data and wider approaches within research and innovation (Lajonchere, 2010).

#### **6.5.5 Positives of the phase**

Generating a co-produced document because of this studies' workshops is the main outcome and positive identified. Specifically, this document was able to utilise stakeholders' experiences to identify the specific topics of consideration for autistic teenage girls, reflecting the nuances identified within this population. Furthermore, facilitating the dialogue between the two stakeholder groups positively impacted the applicability of the result as it acknowledged the key areas identified by each.

Stakeholders were thoroughly committed to the project and thus contributed their time, experiences, and knowledge to this report, ensuring it was a true example of co-production. This was undoubtedly impacted by the efforts taken to build a rapport, establish boundaries and define expectations at the beginning of the phase. The method enabled stakeholders to contribute in a way that was comfortable, being reflexive to ensure that all contributions were viewed equally. Whilst not intentional, utilising the chat function throughout the live workshops enabled a validation of themes or comments to be made. Each of the three themes was supported by an additional concept to support it. Theme one of a collaborative process is supported by the need to balance the needs of professionals against personalisation. Theme two of positioning autistic people in the centre is supported by the broader cultural shift. Theme three of the profile being a living document was supported by its role as a proactive not reactive document.

#### **6.5.6 Power**

The theoretical concept of power was identified in the workshops as a factor that influenced both autistic and professional stakeholders. Where professional stakeholders viewed their power in advocating for the needs of autistic people, this was also viewed as a method of exploitation for professionals who were not as aware of the needs of autistic people. There was the discussion of the links between power in decision making surrounding the support autistic people receive and decisions about their support. It was interesting that professionals identified that their power to act was undermined if there was not research or prior experience did not value an alternative approach. This included the discussion by both autistic people and professionals and research and multimedia in shaping the views and perceptions of autistic people in society.

Autistic people described their feelings of power when feeling able to articulate themselves, when they felt heard and when they could make decisions. However, this experience was considered scarce and unlikely to happen. For autistic stakeholders,



power was often associated with negative experiences, linking to the perceived hierarchy when discussing who knows best. The theoretical concept was represented during the workshops as something autistic people have in their expertise. This provided a new perspective, however, the previous negative experiences resulted in a high degree of scepticism.

When considering power, links were described to the power of decision making. The links between power and capacity to make decisions was an area that autistic stakeholders felt was often misunderstood. The view of autistic people as vulnerable and in need of protection was a position that they felt they contended with when voicing their opinions.

Overall, the concept of power presented various elements that intertwine with hierarchy in society and the information that is considered to be correct. The stakeholders identified their own power to make change as being enhanced through participation and collaboration with research. For autistic stakeholder, being given the tools and adjustments so they can articulate their needs was identified as a shift they would relish.

Through the coproduction nature of the workshops and the positioning of the researcher as a member of the autistic community, it was considered that the potential power dynamic was reduced, as such, allowing for more in depth and open discussions to be had.

#### **6.5.7 Limitations or changes that would be made upon reflection.**

One of the limitations of this phase relates to the demographics of the stakeholders. Firstly, the lack of representation of autistic females under eighteen is a considerable area for development. Whilst the reason for this is unknown, it is postulated that the Coronavirus pandemic was an influencing factor, as during recruitment (early 2021), education was significantly disrupted. Secondly, for autistic stakeholders, their current

education or employment status was identified through discussions, as a result, it may be appropriate in future work to include this information as this is likely to influence their positions. Autistic stakeholders were largely in education or employment; therefore, care should be taken in generalising the experiences and views to individuals not in education or employment. The professional stakeholder group was varied in the disciplinary background, providing a range of experiences. This considered, to gain a specific understanding of the implementation of this report in practice in each discipline, for example, education settings, further work is needed to gain a wider understanding of the positions of the sector, rather than that of individual stakeholders.

Overall, utilising an online approach enabled stakeholders from a wider geographical area to participate. Though, there is the potential that willing stakeholders were excluded as they had no access to digital technology or were not aware it was taking place due to the solely digital and online recruitment and promotion. As participation offered stakeholders no financial incentive to take part, stakeholders that did get involved are likely to view this area of work as important. Conversely, through feedback and discussions with autistic stakeholders, knowing that professionals received no financial incentive or reward for taking part was reassuring.

#### **6.5.8 Summary**

This chapter demonstrates the journey from exploring the literature, designing the phase, co-producing the report, and analysing findings. Further, it has explored themes highlighted in previous chapter, acting as a process of validation. This phase generated a large amount of rich data through verbal and written contributions from stakeholders, with these contributions guiding the direction of the workshop structures and the purpose. The report produced gives a comprehensive summary of the topics and concepts the stakeholders viewed as important for autistic teenagers, with the tailoring of the one-page profile being framed on the specific needs of females.

## **Chapter 7: Discussion**

### **7.1 Introduction**

This thesis presented three phases utilising a range of designs: a scoping review (chapter four), a Foucauldian discourse analysis (chapter five), and a participatory qualitative phase (chapter six). The overall focus, and positioning of this study, fits within the multi-disciplinary area of autism in females, adolescence, and the social world. In addition, the overriding worldview and epistemology enlisted for this study is presented in chapter three, whilst also outlining the design and analytic tools used in each of the phases. An iterative process was adopted throughout, with the narrative review (chapter two) guiding the scoping review. This then prompted the selection of an alternative source of newspapers to conduct a Foucauldian discourse analysis (chapter five). Lastly, in chapter six, each cycle of the workshops were guided by all stakeholders, rather than following a predetermined structure.

This final chapter draws together the key themes across these phases and presents the applications and contributions to wider knowledge. The research questions posed at the beginning of this thesis are also reflected upon.

### **7.2 Unique contributions of this thesis**

The contributions from the three studies will be discussed in turn.

#### Scoping review

This phase was the first to utilise this design exploring the experiences of autistic teenage girls, which is the main contribution. It contributes to the growing dialogue between autistic people and academics when shaping the research priorities.

#### Discourse analysis

This phase contributes a comparison across two time-points, again in an approach not previously available for autistic teenage girls. This contributed to an understanding of how autistic people are positioned in the media and by whom. In addition, through utilising data from 2015 and 2019, the review was able to highlight some of the shifts starting to emerge in how autism is positioned.

### Coproduced phase

This phase co-produced a report that is in the public domain, presenting contribution to real life. From the researcher's position, this was the sought outcome before commencing the PhD. Further, through utilising a fully online approach, it contributes to the growing field of online qualitative online research, or 'netography'. Through the stakeholders' contributions, this approach was viewed as more accessible and inclusive, contributing to an awareness of ensuring that research is open and a space that autistic and neurodiverse individuals can enter.

## **7.3 Findings in context: Overview of Key themes**

Prior chapters have provided an in-depth discussion of the findings and themes generated through each of the individual phases. This section seeks to draw from these the key themes to reflect on them in the context of the whole study as a single contribution to knowledge. The overarching link between each phase is the positioning of autistic teenage girls within the social discourse around their social worlds, with the identification and understanding of these allowing for meaningful and authentic participation within this research.

### **7.3.1 Scoping review**

The scoping review identified the prevalence of standardised measurement tools as a means of data collection, embedding these with considerations of statistical significance. In addition, there was evidence of more participatory and collaborative tools within some articles, though these were in the minority. Whatever the approach, autistic people were positioned as subjects of the research process, with researchers using measures to gain an understanding of experiences and concepts. This was also evident in how autistic females were described, often as a proportion of a larger sample of males and females. When females were included, they were in comparison to autistic males and neurotypical individuals, which did not provide an insight into the real-life experiences of autistic women and girls. In utilising second hand or proxy-reports, autistic people are limited in how their voices are included in research. With

the limits placed upon the articles included in the review, the range of concepts and disciplines that need to be understood were identified.

Through the descriptive quantitative analysis and qualitative thematic analysis, the seven key themes map out the current discussions in academic research. Gaining an understanding of these is a useful tool to guide further work, however caution should be applied as the authentic autistic voice was small within the data set collected. Upon reflection, these themes reflect real life experiences that autistic people face, giving a real-life application and area of where authentic experiences would be beneficial. For example, the themes of social relationships, impacts, the social world, and coping strategies would enable professionals to support and understand autistic people more effectively.

### **7.3.2 Discourse analysis**

The discourse analysis highlighted the range of news articles and possibilities for action. Additionally, through the two time points studied, tentative conclusions of a shift to a social model of disability was identified. It is suggested that the analysis is repeated to include more recent articles to identify if this shift follows on that trajectory. Drawing on positioning, autistic people were predominantly involved as a subject of articles, with their experiences being used to contribute to wider discourses. Though, it was interesting to identify the role of autistic writers to the articles included in analysis. Specifically, this highlighted the role of autistic people in guiding the narratives and discourses available within the media.

Upon reflection, the role of personal narratives in news media is like the increasing participation in research, whereby autistic voices are included in shaping the narrative. However, the articles that draw on medicalised lexis and deficit positions are likely to attract a high readership and thus influence public opinion due to their presence in the early pages and sections of publications and categorisation as 'news'.

In reviewing the articles, analysis included consideration of the purpose of it being published at a given time. For example, where a significant event occurred which increased the social prominence of the topic area. Whilst not a primary function of a discourse analysis, it is likely that the purpose influenced the discourses and positions drawn upon. When considering the two datasets there was a range of commentary from external sources, including parents, teachers, and academics. Though, the autistic person, or subject, did not have any direct quotes or contributions included. In fact, the only autistic narrative provided was through the articles written by an autistic author. To conclude, the discourse analysis enabled topic areas and positions to be identified, thus guiding the subsequent phase.

### **7.3.3 Co-produced qualitative phase**

By the nature of being co-produced, the empirical phase was guided by the previous phases, the researchers own position and the stakeholders. The use of an online approach was an enabling factor to engage with a range of stakeholders and reducing barriers for participation, specifically those that in person research may have presented for autistic stakeholders. The phase identified several areas that were of importance to the stakeholders, including the importance of autistic people being involved in their support and wider training.

The phase enabled stakeholders in various positions to engage and contribute to a shared discussion and focus. The benefit of this was to create findings and applications that meet the needs of autistic people and professionals. Overall, the role of collaboration in any research and practical developments is likely to generate the most positive outcomes.

To summarise, this phase identified several topic areas viewed as important for autistic teenage girls and the wider social constructs and definitions that should be embedded in practice. Though, the greatest contribution is the report produced that included the background to topic areas, the structure of the new tool, and guidance about the way to complete it.

### 7.3.4 Process model of stakeholder engagement

The co-production element of this study is visualised through figure 12, inspired by the process model of stakeholder engagement (Bal, Bryde, Fearon & Ochieng, 2013). This identifies the stages involved with stakeholder engagement, the tasks within each, as well as the continual process. Initially designed in construction sector, it provides a clear model that focuses on the process of engagement, rather than achieving the outcomes set by researchers. This model reflects the stages undertaken in the study, as well as including the amendments that would have been made in retrospect. Whilst each phase identified specific aims, this process model draws on the overall themes identified within the thesis.



Figure 12: Process model of stakeholder engagement.

- Who and what?

This stage acts somewhat like a scoping review in identifying the stakeholders appropriate to the topic area and the sources available. These are then used to set objectives, measurable outcomes and prioritise the focus for the work undertaken.

- Review and do

This stage provides a reflection on previous research through engaging with others, aiming to highlight the gaps that the work seeks to address. Also embedded in this stage is the initial engagement with stakeholders, where building a rapport and sharing experiences is required. The purpose of this engagement is to set stakeholder objectives, which will help to measure the outcomes.

- Make engagement better

Following from the previous stage, here the focus is developing the engagement with stakeholders to produce meaningful outputs addressing the research aims. Again, reflection is positioned in this stage in ensuring the methods of engagement are accessible, whilst also suitable for the subject of study and the aims identified by the researchers and the stakeholder groups.

- Bringing it together

This stage seeks to evaluate findings in response to the research aims and objectives. Furthermore, this includes a reflection on stakeholder involvement and contributions, highlighting the most successful method used. This stage is likely to occur towards the end of a project, therefore, deadlines should be set to ensure any conclusions or implications for practice are transferred appropriately.

- Act, review, do and report

This is viewed as the final stage in the process of stakeholder engagement. Mirroring processes debriefing, it is viewed as a reflective process, that also identifies any follow up or further engagement required.

- Significance, completeness, and responsiveness.

Underlying the stages detailed above are significance, completeness, and responsiveness. Researchers should be aware of these throughout the engagement and research processes.



Whilst the profile version produced in this phase was coproduced (Stark *et al.*, 2020), it is important to recognise that stakeholder engagement is not a one-time process. As such, this version was created at a specific time with the stakeholders, but continual engagement with stakeholders should be embedded in regular practice. There is no set time that should be allocated to prompting the process to recommence in the act, review, do and report phase, however, there are some factors which may indicate this is needed. For example, when a change to policy is shared or when there is a change in how a service is being delivered. It is proposed that this model of engagement can be applied to a range of topic areas that include groups that are described as vulnerable or hard to reach. When focusing on the one-page profile variation created, the potential future research should follow this model.

#### **7.4 Reflection on aims set out in chapter 1**

1. To explore how autistic teenage girls are positioned.

The positions of autistic people in society have emerged through each of the studies, with these positions linking to the output or type of activity undertaken. The predominant positions of autistic teenage girls in each of the studies were identified and are summarised below.

Within the scoping review, autistic teenage girls are frequently positioned as the subject of testing or analysis for academic research, purposed for a range of aims, for example, understanding a phenomenon, evaluating a tool, and testing a hypothesis. Whilst this was not unexpected, it reinforced the need to engage with wider outputs to appreciate the complexity of the topic. Where real life experiences were sought, these often were considered as a product of the research rather than as insights that could be used to identify research priorities.

Within the discourse analysis, autistic teenage girls were primarily the subject of the news article, being described by the author but not engaged with. This included

individual experiences, for example in education, and more broad discussions about the current understandings of how autistic females present and experience the world. When positioning autistic people as the subject, this was frequently accompanied by second-hand accounts and quotes from those in the social support network for them, rather than direct quotes. This can be interpreted in several ways, however the researcher felt that this reinforced the position of autistic people as vulnerable and needing protection. However, when comparing the two time points in this phase, the of positioning autistic females in a mainstream outlet demonstrates small changes indicative of a shift towards inclusion and a social model of disability.

The stakeholder engagement phase drew upon the positions identified in the scoping review and discourse analysis to inform the design and strategy to ensure the research was authentic and driven by stakeholder needs and priorities for research. This resulted in the clear commitment in this study to position autistic females as experts, with this extending to informing the support and environments they experience. Autistic females reinforced the need to dislodge the current hierarchy when considering expertise and knowledge, as this influences the positions of both groups of stakeholders.

Overall, autistic females' positions vary across the studies, with these positions often influenced by other contributors. It would be useful in future work to seek the thoughts and interpretations of autistic individuals when reviewing academic publications and news media.

## 2. To identify the topics and concepts of important consideration for this group.

For autistic females who engaged in the empirical phase, the perception of others about their autism was considered important. This included the negative psychological impact when these misconceptions and assumptions are expressed. A focus within this is linked with their identity as being autistic. Varying opinions about the role of an autism diagnosis were expressed, however, a diagnosis was positioned as a necessity to get support, with it being sought to meet the needs of the organisational systems.

Another concept that was viewed as important was the challenge of receiving support. Specifically, autistic stakeholders described that presenting in a different way to the 'autistic norm' was counterproductive as they were subsequently viewed as functioning and thus not needing support.

The autistic females involved in the phase described how they often navigated the mental health services before receiving a diagnosis, with challenges emerging where they had a dual diagnosis. This reflects the importance of a holistic approach to supporting and understanding autistic females.

The concept of research was viewed sceptically by both autistic and professional stakeholders due to their previous experiences of it. Specifically, the perception of certain roles and viewpoints being viewed more favourably due to social and organisational structures.

3. To gain an understanding of how autistic teenage girls navigate their social worlds.

The social world focus was identified in the search sequences for the scoping review and discourse analysis. This aimed to collect articles which contributed to understandings of how these were navigated. As the thesis developed, it transpired that this was not a focus for autistic people as they described navigation as something they 'just did'. In comparison, other findings highlighted that camouflaging was a large influence on how autistic people experienced the social world. The scoping review identified that coping strategies, such as spending time alone, were highlighted as a theme in articles. It is therefore postulated that navigation is conceptualised by the other actions autistic people take to manage their anxiety and ability to cope, rather than actively seeking to navigate the social world. Examples of navigating the social world were directly observed through the online stakeholder workshops. Through

these, autistic people managed their participation by choosing their preferred method of contribution.

Within the discourse analysis, the media was the source of data to be included. This is considered an element of the social world that autistic teenagers may be aware of. Whilst not addressed specifically in this thesis, it provides an avenue of information stakeholders access which may influence their perceptions and beliefs about autistic females.

4. To engage with stakeholders to support understanding and consider the applications to the wider community.

Through engaging with stakeholders, the complexity of understanding and supporting autistic teenage girls was apparent. Further, the wider shift necessary to embed inclusion in all areas of society was cited, presenting key areas that need to be acknowledged for all individuals with additional learning needs.

Engaging with stakeholders reinforced the researchers' personal experiences and understanding that supporting autistic females without an underlying intellectual disability were often missed or not suitably supported. Specifically, this was highlighted as linking with mental health challenges that were described as the only reason support was considered. From the other stakeholder group, professionals, it appeared that there was a limited, if any inclusion of autistic experiences or input into developing and delivering training or awareness events. Professionals contributing to this thesis were all motivated to engage, with the willingness to apply anything learnt to their practice, though, they cited that this was not something they felt all professionals would do.

When considering the wider community, this phase presents themes identified in news articles, published in national newspapers and thus with a high level of reach among society. It is acknowledged the members of society may not have heard the term

'autism', nor understand what it means, so expecting an understanding of the nuanced presentation of autistic teenage girls would be unrealistic. However, it is proposed that the applications of this thesis are for society to acknowledge diversity, rather than seeking to isolate these topics and narratives to a separate community.

Engaging with stakeholders in this study included positions and beliefs implied through written discourse and verbal interactions surrounding autistic females, autism more broadly and the views of disability. Utilising the voices of stakeholders in the coproduced phase, it is proposed that the main application to society goes further than acknowledging the presence of autistic people to include understanding that autistic people are present at all levels and all areas of society.

5. To consolidate understanding by enlisting a participatory approach with key stakeholders.

Utilising a participatory approach allowed for a diverse range of experiences and personal narratives to be shared. Developing the safe space for these discussions to take place enabled both groups of stakeholders, autistic females, and professionals, to gain an insight into the other's experiences. Through informal discussions throughout the construction of this thesis, several topics presented, which alongside the secondary data analyses, influenced the design and approach for the final phase.

This aim was initially positioned to define and conceptualise key topics which feature in autism literature, for example, camouflaging. In some respects, this was achieved, through gaining lived experiences of the topics and the interpretation of the meanings ascribed to these by individuals. Though, a more prominent conclusion within this aim was the position that the knowledge valued was typically that validated through scientific rigour. In turn, this was positioned as a restrictive factor when experiencing autistic females who often did not fit the perceived conceptualisation of autism. In addition, it was described by autistic people and professionals alike that simply understanding a term or concept was not sufficient, with more value being ascribed to

responding to the needs of autistic females and embedding reasonable adjustments into practice.

The increase in literature and discussion of the experiences of autistic females only reinforces the role of scientific rigour, though, the real-life impact of these findings often does not result in real life positive change or experiences for autistic people. Through engagement with stakeholders, it is suggested that the 'problem' is not the research itself, but rather the processes that are undertaken to decide the research priorities, as these are not viewed as inclusive.

Consolidating understanding also applies to the researcher's own position about the role of research in improving the experiences of this group. Specifically, the shift from seeking to identify the topics and their applications, to using these as framing for the specific needs every individual has without being bound by diagnostic labels or terminology.

Overall, the stakeholder engagement throughout demonstrated that there needed to be a more reflexive and iterative relationship between research, practice, and real-life experiences.

## **7.5 Applications**

The initial application of this thesis comes from the report generated through the stakeholder phase. The report was shared initially with all stakeholders involved in the phase, who were made aware of their ability to share the document among their communities. Subsequently, this report was prepared for strategic sharing to a range of stakeholder groups, including local authorities, autism services and third sector organisations, using information collected in the recruitment process. To reflect the range of stakeholders, this dissemination included sharing on social media and other networking platforms to reinforce the diversity of stakeholders. This was done by creating a bilingual invitation to access the report and consider utilising or sharing it

with their networks. A record was kept of who was contacted with the invitation and those who had responded to aid the identification of the geographical reach of the work and its impact.

A further application of the report is its presentation at a range of enterprise events to develop the application of the findings, specifically to develop a digital platform to host the profile. At present, the author is working with an industry partner to develop this tool to be used in a range of settings in Wales, which will include applications for funding and engagement with additional stakeholders. Within this, the autonomy of autistic people is the primary focus, service users controlling the information inputted into the platform, how much is shared and who to.

It is hoped that through the partnerships identified above the report produced can be transferred into a tool that can be used within the community, thus having an impact on autistic people's lives.

### **7.5.1 Contributions to the autistic community**

To fulfil the researcher's position, it was important to reflect upon the contributions of the studies included in this thesis to the autistic community. Specifically, the output of the one-page profile report was described by stakeholders as something they would use within their lives. The design of the workshops being participatory was credited by stakeholders who felt that research did not always focus upon things that affect them. Whilst the aims did not include identifying the priorities for research, the discussions highlighted the importance of empowering autistic people to contribute to research to ensure that it remains beneficial and useful.

Enabling autistic people to get involved in the research through coproduction was viewed as a contribution to the community, specifically, it is likely that this would encourage others to read the report knowing that autistic voices were instrumental within its creation. The two secondary data analyses, whilst not involving autistic

people's contributions, highlight the positions of autistic people, with the researcher challenging these positions and the often-second-hand accounts, describing these as limitations.

The content included in the coproduced report has been disseminated to stakeholders, including autistic people, their families, and professionals across Wales. It is likely that the sharing will snowball further to become a source of reference, in turn, providing a resource for autistic people, produced by autistic people.

## **7.6 Reflexivity**

Within qualitative research, a core component involves acknowledging and reflecting upon the researcher's worldview, experiences, and assumptions. Specifically, how these beliefs and views may shape findings (Jootun, McGhee & Marland, 2009). Decisions about the direction of research and interpretations of data are both areas where the researcher is central. Reflexivity presents a balance by allowing the reader to develop their own thoughts, interpretations and conclusions from the information provided (Gentles, Jack, Nicholas, & McKibbin, 2014). Providing an insight into the researchers position and prior experience through the preamble seeks to provide context, as objectivity cannot be assured.

This section provides a first-person reflection of the process of producing this thesis and completing the studies included. At various points, obstacles presented which required the plans to change. This primarily relates to the impact of the Coronavirus pandemic and being unable to complete face-to-face activity, presenting a choice of whether to adapt the approved phase design to be completed online, or to seek an alternative approach. In making this decision, reflection focused upon my own motivations for commencing a PhD, namely, to conduct research that is desired by the autistic community. As a result, this phase was concluded, with an alternative phase using secondary data analysis implemented to ensure that it could be completed with the restrictions in place at that time.



Regularly updating a personal journal and decision log throughout the entire study period enabled me to reflect upon the decisions made at various stages and the rationale for these to be made. These records helped me in the latter stages of writing this thesis in drawing together the three studies and the underlying themes identified across them. Furthermore, my personal journal identified considerations of my position and how this influenced the decisions made throughout the entirety of the study period. When decisions were made, this journal was a useful tool to reflect upon the chain of decisions and actions undertaken previously, including the decision to seek a PhD.

Being autistic acted as a continual motivator to continue despite the barriers that presented themselves. Specifically, being part of this community meant that I was also involved in the social networks, witnessing first-hand the potential benefits and real-world applications of my findings. Through the discussions with stakeholders throughout the studies has enabled me to gain a network of peers whose contributions have been beneficial in making decisions and becoming an independent researcher.

At times, the evolving process of understanding was a challenge, though, retrospectively I now identify these stages allowed for the final thesis to all fit into a natural place. It is worthy of mention that my position as part of the autistic community often provided an additional motivation to ensure this thesis fulfils the regulatory requirements of a PhD as well as having applications and relevance for autistic people.

It was a pleasant surprise that I was quickly successful in generating interest in the study, which lead on to a higher-than-expected number of stakeholders being involved. This was monitored to ensure that I was able to manage the number of stakeholders without compromising the method and quality of work. Several avenues to aid recruitment, for example, follow up phone calls, were not needed because of the recruitment success, thus, allowing more time to be placed in preparations for the workshops. My position within the community provided me with an insight into the stakeholder groups that may want to contribute to the study, in addition to the best

ways to engage with them. When conducting the two secondary data analyses, managing the number of results and breadth of data was overwhelming at times.

As someone with lived experience of being autistic, I was able to engage with autistic stakeholders authentically, rather than having to adapt my communication style to embed myself into the community. Being a member of the community also added value when considering the wider impacts of my work, as I have both a personal and professional understanding. Being aware of my own experiences enabled me to identify likely barriers to participation, groups that I should engage with, and tensions in the community. An example of a tension in the community is the use of Applied Behavioural Analysis for autistic children.

This topic has links with a wide range of other specialist topics which interest me, which needed gatekeeping to ensure that the thesis remained focused. At times this became overwhelming, however, as the studies progressed and themes identified, this became less prevalent. Overall, I feel a sense of achievement in completing this thesis and contributing to a community I am part of. Retrospectively, the barriers which presented have likely improved the outcomes and outputs associated with the work, as all pieces of the metaphorical puzzle fit together.

## **7.7 Recommendations**

### **7.7.1 Policy**

In generating policy that impacts autistic people, it is crucial to include an element of engagement with the community throughout it. Drawing upon lived experiences of autistic people and their families can enrich the applicability of policy, potentially identifying possible gaps or areas needing further clarity that professionals may not. Furthermore, engaging with broad range of stakeholders is important to ensure that policy designed can be understood and be implemented appropriately across all settings. Discussing this topic, Roche, Adams, and Clark (2021) describe how individual studies have identified the research priorities of specific groups in the autism community, though these have yet to be considered collectively. Policy should focus

on enriching all aspects of an individual's life and social world, whilst acknowledging that best practice may not all come from academic or professional lead publications.

The importance of viewing autistic people as central and autonomous human actors is crucial in any policy that involves their experiences, whether that be health care, education, and other elements of life. The Code of Practice on the delivery of autism services (Welsh Government, 2021a) describes several ways that this will be done with the implementation of this new code.

Specifically, through its impact assessment, it describes how they will '*promote the involvement of autistic people in the design and delivery of the services they receive*' (Welsh Government, 2021b: p.5). It also utilises the terminology of 'stakeholders' to describe the creation of the code and the partnership with '*autistic people, their representatives, health and local authority stakeholders, third sector organisations and Welsh Government departments*' (p.6). Further, it describes the procedures and safeguards in place throughout its implementation to ensure that this involvement continues, for example, an Autism Advisory Group to seek autistic members' feedback on the delivery of the code (Welsh Government, 2021b). As this code became active after the phases in this study were completed, it would be beneficial for these findings to be shared as this policy is reviewed and monitored. For those seeking to view a practical application of stakeholder engagement, including those seeking to conduct research, this study may provide a source of reference as it embeds the principles of the code through the participatory approach and stakeholder engagement.

The one-page profile already is described in policy surrounding individuals' reviews, however, the version produced through this study is suited to inclusion in policy in a broader range of sectors. When considering policy, this thesis reinforces the importance of flexibility in the suggestions made. A one-size approach does not meet the needs of the autistic community, and it is therefore recommended that policy utilise the underlying components and aims, rather than prescriptive tools and pathways that do not allow for the variability of autism.

### **7.7.2 Practice**

Throughout the three phases, there were embedded assumptions and stereotypes which stakeholders described as influencing their lived experience. Going forward, practice should acknowledge these, with professionals taking a role in challenging these. To enable best practice, engagement with stakeholders, including autistic people is seen as beneficial to deepen understanding.

Through this work, the version of the profile can be shared across the peer and professional networks within the autistic community as a source of information for individuals and their families. Whilst expectations of the use of this need to be realistic, utilising established networks to disseminate among the community would ensure that research is not ringfenced to academic communities.

The version of the profile created in the empirical phase provides a tool that can be utilised in practice immediately. Being accessible for free to autistic people and professionals increases the accessibility of the document. Other practical applications of the report are that it can be used as a source of information around topics such as camouflaging, stimming and inclusion.

When focusing on the delivery of autism training, it is important that autistic people are involved at all stages of planning, delivery, and evaluation. Similarly, to other training, such as first aid, an individual must demonstrate a competency in a role play scenario in order to gain the accreditation. It is suggested that this is embedded in autism training to ensure that training does not become tokenistic, and the learning is embedded at a deeper level. Suggestions for how this could be done is included having a conversation with several autistic people part of the training.

### **7.7.3 Future research**

When considering the applications of this thesis, future research is central in ensuring that it continues to reflect the needs of the autistic community. Specifically, this includes continuing to engage with all relevant stakeholders to develop understanding. Another suggestion is that online methods of engagement remain an option in research to ensure that autistic people are empowered to engage in a way they feel most comfortable. In the present study, allowing flexibility in the method of participation was described as a deciding factor in whether someone took part or not.

Focusing on the one-page profile version generated through the empirical phase, the primary research required pertains to implementing and evaluating it in the daily practice for autistic teenage girls. For example, this would need to consider how it would be managed and the responsibilities for ensuring they are used appropriately. In addition, work should broaden to include a wider neurodiversity narrative to reflect the varied needs this population has. Evaluating its use and gaining feedback from autistic stakeholders is an important aspect of continuing the process model of stakeholder engagement.

What has emerged through this thesis is the influence of research, though it may not always be driven by the needs of the community it seeks to investigate. Specifically, the scoping review identified the focus of academic literature in the topic area, where there was a lack of participatory methods and contribution from autistic people. Research was utilised to add credibility and perceived truth in the articles included in the discourse analysis. Whilst this does have its merits, the context of the articles overall presented a stereotypical view of autism.

Through stakeholder engagement at various stages throughout these phases, a perception of research being distanced from real life was implied. Whilst this was expected from autistic people and the academic world, there were further thoughts of disconnect between professionals and research, with views that the practicality of suggestions was not always feasible or achievable outside of the research

environment. As a result, it is suggested that future work engages with stakeholders to ensure that research is meeting the need of autistic people, whilst also acknowledging the specific nature of the environments they inhabit, and professionals involve.

#### **7.7.3.1 Specific suggestions for future research**

The primary suggestion arising from this research is the use of the one-page profile for autistic teenage girls in Wales. Through this, the tool could be adapted and amended to align with policy, specifically the ALN code of practice. Included in this would be research to further develop the feasibility of utilising this tool and the roles and responsibilities of various actors, including individual professionals, establishments, and local authorities to ensure that they are used correctly. It is acknowledged that no autistic females in early adolescence (13-17) were involved in the phase, leading to this being highlighted as a clear aim in developing this tool and ensuring it meets the needs of the people it focuses upon.

Other potential research directions include:

- Utilising the content included on one-page profiles to shape autism training and prioritise the autistic voice in creating this.
- Exploring the use of a one-page profile in key time periods in one's life, for example, moving to college, the transition to adult services, and having a change in support being provided.
- Expanding the use of the one-page profile to other settings such as workplaces and community settings.
- Future research may also seek to adapt this tool for other additional needs, to reflect a holistic model of needs that does not focus on single diagnosis or labelling. Through this, the application would be to a much wider audience and therefore a technological element to its use would be beneficial. It is likely that expanding the scope of this tool would encounter wider social constructs, such as moving towards a model of neurodiversity, rather than focusing upon labelling.

Overall, the themes identified in all three phases support the focus of research as being the needs of autistic people, improving experiences and well-being and enabling them to reach their full potential. Future research should position autistic people as actors in the development of new ideas and theories, rather than participants subject to the ideas and desires of the academic community. Researchers should involve stakeholders in all elements of the research, including designing the method and mode participation will entail, as this study demonstrates the benefits of responding to the needs of autistic people in deciding how participation will take place. In doing this, researchers will challenge any questions of tokenism, which the autistic community often describe.

### **7.8 Reflection on prior literature**

The role of language and descriptions of autism was identified at the start of this thesis as a potentially important topic. Through the scoping review and discourse analysis, linguistic choices often drew on medical descriptions. In comparison, the stakeholders in the empirical phase expressed an overall dislike to these terms and reinforced the importance of asking the person as everyone will have their own preferences. These findings mirror Sousa (2011) and Langan (2011) in language being influenced by the role of autism to them. Through discussions with stakeholders, language was positioned as a mechanism that influenced how autistic people viewed those engaging with them. For example, when expressing a preference about language use, autistic people described that people following it would build up trust and feelings of being autonomous. In comparison to addition literature, this study highlighted that some autistic people viewed language as a way to describe a diagnosis, without the perceptions and implications derived from it. One stakeholder described as needing to use the term 'Asperger's' as it was the term used on their diagnostic report.

When completing the one-page profile phase, it was evident for all stakeholders that the tool had the benefit of outlining an individual's needs so that all professionals were equally informed. Additionally, this strategy acknowledged the potential for strategies and support to be dismissed if an autistic person camouflages or masks their

experiences (McPartland, 2019). Whilst camouflaging is described as an adaptive strategy, it may act as a barrier for someone to recognise an individual's level of anxiety and needs. Within the one-page profile, highlighting the support an individual needs, their coping strategies, and signs of becoming overwhelmed sought to overcome this.

## **7.9 Strengths and Limitations**

Overall, each of the three phases of this study provided a unique contribution as the methods employed had not previously been used in the topic area. The overall design of each phase in this study utilised a recognised framework, enhancing the credibility of the themes identified. In addition, these specific frameworks, for example, thematic analysis, enabled contributions to be meaningful to the overriding aim to surface autistic teenage girls' experiences, ensuring a clear interrelationship between the phases, rather than segmented stages. Another strength of this study focuses upon the participatory nature and engagement throughout with stakeholders to ensure that the authentic autistic voice is considered the gold standard, rather than the views of academic research or clinicians. Another key strength of this study is the holistic nature of data collection, utilising a range of sources to ensure a full emersion in the complex social discourse. The researcher's position as an autistic female is framed as a strength of this study, both through understanding the topics discussed and shaping the design to be accessible for true participation and co-production.

Limitations of each of the three studies are discussed in their correlating chapters (see chapter 4 – scoping review, chapter 5 - discourse analysis and chapter 6 – empirical phase). This section will broaden the scope to the overall thesis to avoid replication.

Throughout this thesis, it was decided to not provide a comparison to non-autistic teenage girls as the methodological approach supported the focus on autistic teenage girls in Wales. However, it would have been beneficial to explore the experiences of this group to develop an understanding for professionals of the breadth of experiences.



It is noteworthy that this thesis did not consider the role of gender identity for autistic people. As such, it is limited in possible applications for autistic individuals who do not identify on a binary system of gender. This is a growing area of research; however, it was beyond the scope of the thesis to consider this alongside positioning. The use of a gender specifier for this research was to ensure the study was focused, arising from prior research that identified females as experiencing autism in a specific way.

A factor that may be considered a limitation is the vast geographical location of the research included in the literature on this topic, compared to the specific focus in the empirical phase in Wales. When considering this, the bilingual nature of Wales was not considered as a factor that may affect how autistic females experience the social world. Whilst all stakeholder information was provided bilingually, the lack of access to a Welsh speaker to conduct discussions and workshops with stakeholders is considered a limitation. The one-page profile that was used to scaffold discussion in the first phase of the online workshops reflects the educational and social structures in Wales, though several stakeholders had resided in different areas during their lives. As such, there is a potential for stakeholders to have included experiences outside of Wales.

It may be viewed that a lack of an industry partner or funding body to be involved with this thesis is a limitation, however, this is a subjective view of which multiple perspectives present. These include the benefits of not having restrictions in the direction of the research so that the needs of the autistic community and stakeholders could be prioritised. On the other hand, whilst the remit of this thesis was outlined prior to registration, it did not undergo the processes associated with applying for a funded post, therefore the aims and purposes of the thesis evolved throughout.

## **7.10 Conclusion**

Overall, this thesis presents a multi-designed approach with an underlying theme of the position that autistic teenage girls inhabit within each of the contexts. The iterative process has enhanced the findings, especially when generating data that has

applications to the real-life experiences of autistic people and other key stakeholders. The success in gaining contributions to a vast range of stakeholders is a significant influence in the success of the workshops and the data created. The topics and definitions included in the report are positioned as a source of information for stakeholders to gain an understanding of key concepts. It is hoped that through the sharing of the data generated in the empirical phase, autistic teenage girls, and those around them can use the suggestions to improve experiences and be useful in a real-life setting.

This thesis has given a voice to a group lacking in representation in research, autistic females. It is hoped that these contributions long continue and are viewed as integral perspectives in research, in turn influencing educational, health and social priorities for autistic women and girls.

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## Appendices

### Appendix 1

Search sequence	Search results (number of)			
	<u>Proque</u> <u>st</u>	<u>ERI</u> <u>C</u>	<u>Psychin</u> <u>fo</u>	<u>Spring</u> <u>er</u>
Autism “and” social “and” navigate “or” manage	139	31	134	105
Autism “and” unwritten rules “and” navigate “or” manage	0	0	0	2
Autism “and” female* “and” teenager* “or” adolescent*	910	89	32	14
Autism “and” girl* “and” teenager* “or” adolescent*	187	52	54	5
Autism “and” girl* “and” friendship* “or” relationship*	112	54	196	36
Autism “and” female* “and” friendship* “or” relationship*	388	67	143	2
Autism “and” girl* “and” camouflage “or” masking	8	4	6	18
Autism “and” female* “and” camouflage “or” masking	13	6	59	24
Autism “and” female* “and” emotion “or” mental health	330	38	49	17
Autism “and” girl* “and” emotion “or” mental health	74	15	54	13
Autism “and” female* “and” wellbeing “and” social	12	2	154	32
Autism “and” female* “and” well being “and” social	25	5	72	6
Autism “and” female* “and” well-being “and” social	16	4	61	6
Autism “and” girl* “and” wellbeing “and” social	2	1	2	21
Autism “and” girl* “and” well being “and” social	2	2	11	9
Autism “and” girl* “and” well-being “and” social	1	1	10	2
Autism “and” female* “and” teenager* “and” technology	3	0	2	19
Autism “and” girl* “and” teenager* “and” technology	2	0	0	13
Autism “and” female* “and” adolescent* “and” technology	18	3	115	2
Autism “and” girl* “and” adolescent* “and” technology	5	1	17	26
Autism “and” female* “and” teenager* “and” social media	0	0	2	2
Autism “and” girl* “and” teenager* “and” social media	0	0	0	5
Autism “and” female* “and” adolescent* “and” social media	8	1	49	12
Autism “and” girl* “and” adolescent* “and” social media	2	1	6	4
ASD “and” social “and” navigate “or” manage	47	11	47	0
ASD “and” unwritten rule* “and” navigate “or” manage	0	0	0	2
ASD “and” female* “and” teenager* “or” adolescent*	353	46	55	3
ASD “and” girl* “and” teenager* “or” adolescent*	93	23	121	6
ASD “and” girl* “and” friendship* “or” relationship*	30	11	34	4
ASD “and” female* “and” friendship* “or” relationship*	167	34	39	9
ASD “and” girl* “and” camouflage “or” masking	1	2	2	15
ASD “and” female* “and” camouflage “or” masking	4	3	21	20
ASD “and” female* “and” emotion* “or” mental health	175	23	16	18
ASD “and” girl* “and” emotion* “or” mental health	48	13	71	6
ASD “and” female* “and” wellbeing “and” social	7	1	55	11
ASD “and” female* “and” well being “and” social	16	2	51	10
ASD “and” female* “and” well-being “and” social	7	1	42	10
ASD “and” girl* “and” wellbeing “and” social	2	1	1	6

ASD “and” girl* “and” well being “and” social	1	1	3	16
ASD “and” girl* “and” well-being “and” social	1	1	3	13
ASD “and” female* “and” teenager* “and” technology	2	0	2	5
ASD “and” girl* “and” teenager* “and” technology	1	0	0	1
ASD “and” female* “and” adolescent* “and” technology	7	0	46	25
ASD “and” girl* “and” adolescent* “and” technology	1	0	4	9
ASD “and” female* “and” teenager* “and” social media	0	0	0	10
ASD “and” girl* “and” teenager* “and” social media	0	0	0	6
ASD “and” female* “and” adolescent* “and” social media	4	1	22	25
ASD “and” girl* “and” adolescent* “and” social media	2	1	2	8
Aspergers “and” social “and” navigate “or” manage	6	1	6	11
Aspergers “and” unwritten rules “and” navigate “or” manage	0	0	0	0
Aspergers “and” female* “and” teenager* “or” adolescent*	43	1	272	0
Aspergers “and” girl* “and” teenager* “or” adolescent*	6	1	7	3
Aspergers “and” girl* “and” friendship* “or” relationship*	5	0	4	9
Aspergers “and” female* “and” friendship* “or” relationship*	15	1	67	14
Aspergers “and” girl* “and” camouflage “or” masking	1	0	1	1
Aspergers “and” female* “and” camouflage “or” masking	0	0	1	2
Aspergers “and” female* “and” emotion* “or” mental health	4	0	157	1
Aspergers “and” girl* “and” emotion* “or” mental health	5	0	3	23
Aspergers “and” female* “and” wellbeing “and” social	0	0	2	10
Aspergers “and” female* “and” well being “and” social	0	0	4	2
Aspergers “and” female* “and” well-being “and” social	0	0	2	19
Aspergers “and” girl* “and” wellbeing “and” social	0	0	0	4
Aspergers “and” girl* “and” well being “and” social	0	0	0	0
Aspergers “and” girl* “and” well-being “and” social	0	0	0	11
Aspergers “and” female* “and” teenager* “and” technology	0	0	0	5
Aspergers “and” girl* “and” teenager* “and” technology	0	0	0	3
Aspergers “and” female* “and” adolescent* “and” technology	0	0	4	11
Aspergers “and” girl* “and” adolescent* “and” technology	0	0	1	7
Aspergers “and” female* “and” teenager* “and” social media	0	0	1	0
Aspergers “and” girl* “and” teenager* “and” social media	0	0	0	0
Aspergers “and” female* “and” adolescent* “and” social media	1	0	1	8
Aspergers “and” girl* “and” adolescent* “and” social media	0	0	0	3
Asperger’s “and” social “and” navigate “or” manage	8	1	6	6
Asperger’s “and” unwritten rules “and” navigate “or” manage	0	0	0	1
Asperger’s “and” female* “and” teenager* “or” adolescent*	71	5	306	3
Asperger’s “and” girl* “and” teenager* “or” adolescent*	12	2	20	4
Asperger’s “and” girl* “and” friendship* “or” relationship*	8	0	2	9
Asperger’s “and” female* “and” friendship* “or” relationship*	18	2	74	18
Asperger’s “and” girl* “and” camouflage “or” masking	8	0	1	14
Asperger’s “and” female* “and” camouflage “or” masking	4	0	2	0
Asperger’s “and” female* “and” emotion “or” mental health	23	0	140	26
Asperger’s “and” girl* “and” emotion “or” mental health	7	1	6	9
Asperger’s “and” female* “and” wellbeing “and” social	0	0	3	1
Asperger’s “and” female* “and” well being “and” social	0	0	5	4

Asperger's "and" female* "and" well-being "and" social	0	0	3	4
Asperger's "and" girl* "and" wellbeing "and" social	0	0	0	1
Asperger's "and" girl* "and" well being "and" social	0	0	0	2
Asperger's "and" girls "and" well-being "and" social	0	0	0	2
Asperger's "and" female* "and" teenager* "and" technology	0	0	0	1
Asperger's "and" girl* "and" teenager* "and" technology	0	0	0	2
Asperger's "and" female* "and" adolescent* "and" technology	0	0	6	9
Asperger's "and" girl* "and" adolescent* "and" technology	0	0	3	3
Asperger's "and" female* "and" teenager* "and" social media	0	0	1	1
Asperger's "and" girl* "and" teenager* "and" social media	0	0	0	3
Asperger's "and" female* "and" adolescent* "and" social media	1	0	1	0
Asperger's "and" girl* "and" adolescent* "and" social media	0	0	0	0
Autism Spectrum Disorder "and" social "and" navigate "or" manage	74	22	101	5
Autism Spectrum Disorder "and" unwritten rule* "and" navigate "or" manage	0	0	0	5
Autism Spectrum Disorder "and" female* "and" teenager* "or" adolescent*	509	62	113	5
Autism Spectrum Disorder "and" girl* "and" teenager* "or" adolescent*	142	36	271	13
Autism Spectrum Disorder "and" girl* "and" friendship* "or" relationship*	57	29	89	9
Autism Spectrum Disorder "and" female* "and" friendship* "or" relationship*	217	45	23	15
Autism Spectrum Disorder "and" girl* "and" camouflage "or" masking	6	4	6	7
Autism Spectrum Disorder "and" female* "and" camouflage "or" masking	11	6	48	10
Autism Spectrum Disorder "and" female* "and" emotion* "or" mental health	237	33	30	9
Autism Spectrum Disorder "and" girl* "and" emotion* "or" mental health	72	20	124	24
Autism Spectrum Disorder "and" female* "and" wellbeing "and" social	8	1	99	13
Autism Spectrum Disorder "and" female* "and" well being "and" social	18	3	263	3
Autism Spectrum Disorder "and" female* "and" well-being "and" social	8	2	205	30
Autism Spectrum Disorder "and" girl* "and" wellbeing "and" social	2	1	1	6
Autism Spectrum Disorder "and" girl* "and" well being "and" social	1	1	5	23
Autism Spectrum Disorder "and" girl* "and" well-being "and" social	1	1	5	14
Autism Spectrum Disorder "and" female* "and" teenager* "and" technology	2	0	2	6
Autism Spectrum Disorder "and" girl* "and" teenager* "and" technology	1	0	0	5
Autism Spectrum Disorder "and" female* "and" adolescent* "and" technology	9	1	304	31
Autism Spectrum Disorder "and" girl* "and" adolescent* "and" technology	1	0	5	8

Autism Spectrum Disorder “and” female* “and” teenager* “and” social media	0	0	1	7
Autism Spectrum Disorder “and” girl* “and” teenager* “and” social media	0	0	0	14
Autism Spectrum Disorder “and” female* “and” adolescent* “and” social media	6	1	34	9
Autism Spectrum Disorder “and” girl* “and” adolescent* “and” social media	2	1	4	28
Autistic Spectrum Disorder “and” social “and” navigate “or” manage	36	2	28	0
Autistic Spectrum Disorder “and” unwritten rule* “and” navigate “or” manage	0	0	0	0
Autistic Spectrum Disorder “and” female* “and” teenager* “or” adolescent*	273	10	36	0
Autistic Spectrum Disorder “and” girl* “and” teenager* “or” adolescent*	94	10	132	0
Autistic Spectrum Disorder “and” girl* “and” friendship* “or” relationship*	32	9	42	2
Autistic Spectrum Disorder “and” female* “and” friendship* “or” relationship*	119	10	10	4
Autistic Spectrum Disorder “and” girl* “and” camouflage “or” masking	4	2	3	0
Autistic Spectrum Disorder “and” female* “and” camouflage “or” masking	9	3	26	0
Autistic Spectrum Disorder “and” female* “and” emotion* “or” mental health	130	5	7	3
Autistic Spectrum Disorder “and” girl* “and” emotion* “or” mental health	47	5	58	1
Autistic Spectrum Disorder “and” female* “and” wellbeing “and” social	4	0	32	1
Autistic Spectrum Disorder “and” female* “and” well being “and” social	10	2	88	18
Autistic Spectrum Disorder “and” female* “and” well-being “and” social	4	1	68	2
Autistic Spectrum Disorder “and” girl* “and” wellbeing “and” social	1	0	0	0
Autistic Spectrum Disorder “and” girl* “and” well being “and” social	0	0	2	8
Autistic Spectrum Disorder “and” girl* “and” well-being “and” social	0	0	2	0
Autistic Spectrum Disorder “and” female* “and” teenager* “and” technology	2	0	0	0
Autistic Spectrum Disorder “and” girl* “and” teenager* “and” technology	1	0	0	0
Autistic Spectrum Disorder “and” female* “and” adolescent* “and” technology	6	0	69	0
Autistic Spectrum Disorder “and” girl* “and” adolescent* “and” technology	1	0	4	1
Autistic Spectrum Disorder “and” female* “and” teenager* “and” social media	0	0	0	0
Autistic Spectrum Disorder “and” girl* “and” teenager* “and” social media	0	0	0	0
Autistic Spectrum Disorder “and” female* “and” adolescent* “and” social media	3	0	12	9

Autistic Spectrum Disorder “and” girl* “and” adolescent* “and” social media	0	0	4	4
	<b>5632</b>	<b>895</b>	<b>5333</b>	<b>1255</b>
	<b>Total number of search results 13115</b>			



## Appendix 2

<b>Data sifting - hand search</b>		<b>0</b>
<b>Total articles identified</b>		<b>13115</b>
<b>Stage 1:</b> Number of duplicates		9066
<b>Stage 2:</b> Number of titles screened Number of articles removed		4049 3537
<b>Stage 3:</b> Number of titles and abstracts screened Number of articles removed		512 329
<b>Stage 4:</b> Number of full texts screened Number of articles removed		183 114
<b>Stage 5:</b> Number of texts included Any other exclusions (not having access)		69 6
<b>Stage 6:</b> Number of texts included Secondary exclusions post draft submission		63 37
<b>Final number of studies included in the review:</b>		<b>26</b>

## Appendix 3

DOI	Author(s)	Date	Origin/country of origin
10.1177/0143034317719942	Ahlers, K. P., Gabrielsen, T. P., Lewis, D., Brady, A. M., & Litchford, A.	2017	USA
10.1037/bdb0000057	Ashbaugh, K., Koegel, R., & Koegel, L.	2017	USA
10.1016/j.rasd.2009.07.002	Ashburner, J., Ziviani, J., & Rodger, S.	2010	Australia
10.1007/s10339-018-0866-5	Barendse, E. M., Hendriks, M. P. H., Thoonen, G., Aldenkamp, A. P., & Kessels, R. P. C	2018	The Netherlands
10.1023/A:1016378718278	Bauminger, N.	2002	
10.1023/A:1025827427901	Bauminger, N., Shulman, C., & Agam, G.	2003	Israel
10.1007/s10803-007-0501-2	Bauminger, N., Solomon, M., Aviezer, A., Heung, K., Brown, J., & Rogers, S. J.	2008	USA
10.5897/ERR2015.2429	Bermudez, M. O. E., Sanchez, J. J. C., del Sol, M., & Sevilla, F.	2015	Spain
10.1007/s10803-015-2563-x	Biggs, E. E., & Carter, E. W.	2016	USA
10.1111/jar.12364	Bostrom, P., & Broberg, M.	2018	Sweedden
10.1177/1362361315574888	Bottema-Beutel, K., Mullins, T. S., Harvey, M. N., Gustafson J, R., & Carter, E. W.	2016	USA
10.1007/s10803-018-03878-x	Cage, E., & Troxell-Whitman, Z.	2019	UK
10.108/09687599.2016.1267610	Callus, A-M.	2017	
10.1007/s10803-006-0164-4	Chamberlain, B., Kasari, C., & Rotheram-Fuller, E.	2007	USA
10.1016/j.dhjo.2914.04.004	Chen, Y-W., Bundy, A., Cordier, R., & Einfeld, S.,	2014	Australia
10.2147/NDT.S87844	Chen, Y-W., Bundy, A., Cordier, R., Yi-Ling, C., & Einfeld, S.,	2015	Australia/Taiwan
10.1177/1362361316636756	Chen, Y-W., Bundy, A., Cordier, R., Yi-Ling, C., & Einfeld, S.,	2017	Australia/Taiwan
10.1177/1088357614522289	Clark, B. G., Magill-Evans, J. E., & Koning, C. J.	2015	USA
10.1080/08856257.2017.1312797	Cook, A., Ogden, J., & Winstone, N.	2018	UK
10.1007/s10803-013-1985-6	Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A.	2014	UK
10.1111/j.1471-3802.2012.01246.x	Hebron, J., & Humphrey, N.	2014	UK
10.1186/s13229-015-0044-x	Jamison, T. R., & Schuttler, J. O.	2015	USA
10.1007/s10803-019-03906-4	Milner, V., McIntosh, H., Colvert, E., & Happe, F.	2019	UK
10.1007/s10803-015-2669-1	Sedgewick, F., Hill, V., Yates, R., Pickering, L., & Pellicano, E.	2016	UK
10.1016/j.rasd.2015.11.013	Tierney, S., Burns, J., & Kilbey, E.	2016	UK
10.1016/j.rasd.2016.11.006	Vine Foggo, R. S., & Webster, A. A.	2017	Australia

Aims/purpose
Explore misconceptions of ASD, identify intervention strategies and supports. Focus on social and emotional needs.
Examine the effectiveness of structured social planning in relation to involvement with activities, more interaction with peers, levels of satisfaction in socialisation.
Examine the difference using various measures of individuals with ASD and their typically developing peers. Focused on emotions, behaviour and achievement.
Gain an insight into the mentalising abilities of high-functioning teens with ASD and whether skills measured in labs relate to those in real life.
Evaluate effectiveness of 7 month intervention. 1, solve social problems, 2, emotional understanding, 3, social interaction
Assess quality/quantity of spontaneous social interaction, differences between mixed and non-mixed groups,, social understanding of interaction, understanding of loneliness
Investigate differences and similarities in mixed and non-mixed HFASD and TD (friendship characteristics) and differences in developmental and socio emotional development
Compare parent and self reports of anxiety
Examine SWB of transition age youth, QoL with ASD or ID. 1) parent depict QoL, 2) difference to normative samples, 3) factors predicting QoL
Explores experiences of well-being, mental ill-health, family, school, and peer relations in students in special education.
Part of larger study to develop intervention for secondary school children with ASD, including addressing social competence and peer connections.
Enhance understanding of camouflaging by examining its reasons and contexts, and the potential costs for mental health.
Understand how people with ID experience friendship and what friendship means for them.
Examine how children with autism face challenges attempting to negotiate classrooms. Relationship between self and others' perceptions. Age/gender differences?
To investigate the feasibility and usability of experience sampling method (ESM), an ecological momentary assessment, for studying individuals with ASD.
Examine motivation for the contextual nature of motivations for social participation in cognitively able adolescents/adults with ASD, using self-determination framework
Compare patterns of everyday participation of cognitively able adolescents and adults with ASD across gender/cultural contexts using ESM.
Assess QoL in adolescents, again in parents, evaluate the differences and similarities, examine in relation to adaptive functioning
QoL in youth using self-report, assess using parent-report, evaluate relationship between these, example relationships to adaptive functioning
Investigate experiences of females with ASD and their mothers.
Address limitations in previously reported research and findings. Mental health difficulties in teens with ASD in mainstream secondary schools.
Examine similarities and differences in selected indicators of social-emotional health and problematic behaviours for adolescent females with and without ASD.
Add to previous research. Gather info from various perspectives. First hand accounts hope to improve current understanding
Examine gender differences in social motivation and friendship experiences of adolescent girls and boys with and without autism
Explore whether adolescent females with ASD use social management strategies, specifically masquerading to hide socio communication difficulties in order to fit in with peers
Explore insights and perceptions of adolescent females with ASD regarding social experiences/relationships with female peers. Specific focus on expectations and qualities brought to them

Study/sample
N/A
College/uni students with a diagnosis of ASD, 18-25, fluent language, no history of violence/agression, social difficulties self reported and observed. Normal or above IQ.
Comparison of students with ASD and typically developing peers (same classrooms). 12 schools in total.
Adolescents from specialist secondary education school in the Netherlands. Those with ASD and TD peers acting as controls.
15 children (between ages 8 and 17) with autism
Children/adolescents between 8 and 17. Middle class society with some in a specialist education setting, some in specialist classrooms and some mainstream.
USA and Israel children and peers
aged 7-18, ASD, 70 + IQ
Parents of those with ASD or ID
10 students (aged 13-16), analysed by mixed methods phenomenological research approach
33 met criteria and participated (individuals with ASD between 14 and 25 years)
Autistic adults over the age of 18
Adults with ID in a self-advocacy group who were purposive sample.
Children in regular 2nd to 5th grade classes, including 17 children with confirmed diagnoses. 7 schools in two districts
4 participants (2 males) with Asperger's syndrome or high functioning autism aged 16-32 years. Identified through adverts.
Individuals with Aspergers and High Functioning Autism
32 individuals with ASD, between 16 and 45, average reading ability and IQ.
Email sent to parents on specific hospital database. Diagnosis of ASD, English language, level 6 reading, between 13 and 18, parent consent to participate
Mainstream and special education schools, females, purposive sampling, girls year 7-13, and one parent. 22 interviews (10 mother-daughter, 1 father-daughter)
Females with ASD between 12 and 17.
From 17 secondary schools. Into 3 groups, AS, DYS (Dyslexia) and CON (No SEN)
Individuals with ASD, parents ASD, no ASD. 14-19 years old. Reading at 4th level or above. ability to speak 2-3 word phrases at rate of 1-2 per minute. Exclude aggressive behaviour.
Linked with ongoing larger projects. Female gender or parent of female with ASD, in UK. Aged 11-55. Recruitment: social media, word of mouth, secondary school, autism clinic.
Special educational school enrollment, and in receipt of a statement. Independent diagnosis. Without autism but had a range of other difficulties. 4 matched groups.
Purposive sample: female, 13-19, diagnosis of ASD, comorbid diagnoses included. Practitioner referral and self referral through ASD charities.
Mainstream secondary school. Recruited through ASD support centres, professional organisations and online. Pps and parental consent. All diagnosis by clinician.

Size	Other demographic
N/A	N/A
3 full participation	2 female 1 male
28 (ASD), 51 (TD)	ASD (24 m, 4 f), TD (43 m, 8 g)
21 (ASD), (21 TD)	ASD (1 f 20 m), TD (4 f, 17 m)
15 full participation	4 f, 11 m
35 (18 HFA), 17 (TD)	HFA (2 f 16 m), TD (2 f 15 m)
146 + peers	42 HFA (2 f 40 m), 31 TD (2 f 29 m)
38 (36 m 2 f)	38 parents (22 father 16 mother)
389 children (118 f 271 m)	84.3% mother, 9.3% father, 6.4% other
10 (13-16 years old)	6 m 4 f (IDD + ASD, 5)
33 full participation	11 f 22 m (4 Autistic disorder, 26 AS, 4 PDD-NOS)
262 (18 yo - 66yo)	111 m, 135 f, 12 other, 4 not disclosed
7 ( 5 f 2 m)	Between early twenties and late fifties
398 (196 boys)	17 ASD (14 m 3 f). IQ normal range
4 (2 m, 2 f)	All pps had concomitant mental health diagnoses
14 Australian, 16 Taiwanese	16-45 years, A (4m 10f), T (12m 4f)
14 Australian, 16 Taiwanese	A (4m 10f), T (12 m 4 f)
22 (3 f, 19 m)	21 mum 1 dad, 11 p's at least 1 other diagnosis
11 (6 mainstream 5 special)	6 with comorbidities, 10 white british, 1 mixed race
5 (3 diads and 2 mothers)	3 with additional diagnoses
AS (22), DYS (21), CON (23)	AS (19m, 3f) DYS (17m, 4f) CON (19m, 4f)
23 ASD, 23 pASD, 29 NoASD	Mean age/white: ASD(16.04,91%)noASD(16.75,97%).
18 (ASD) 4 (parent)	ASD (16 formal diagnosis, 2 self diagnosis)
46 (23 ASD 23 non ASD)	ASD (13f 10m) nonASD (13f 10m)
10 ASD (2 with other)	7 mainstream, 1 home educated, 1 PRU, 1 none
7 (all female)	Aspergers (4) Autism Spectrum disorder (3)

Methodology/methods
Review of previous literature
Matched with peer mentor who supported in social settings (met for supervision with clinician).
Autism rating scale from caregivers, asperger caregiver questionnaire, intelligence test of verbal/non-verbal IQ, teachers rating scale, teacher report form.
Child behaviour checklist and youth self report. Self perception profile for adolescents. ADOS module 4. Director task (ToM). Emotion recognition task.
Problem solving measure- emotion inventory, observation and teacher reports
Picture understanding and questions, observations (2x researchers) in 4 15 minute break sessions, define loneliness and rating scale (self report)
ASD + TD observations during tasks, various methods and scales, self report mother interview
SCARED self report questionnaire
Kidscreen 27, various items of self / proxy report, measured on a 5 point scale
Wellbeing in special education questionnaire (WellSEQ) and semi-structured interviews.
Interview (chose one of 6 formats): in person, video chat, phone, mail, email, and instant messaging. 4 members conducted interviews, after having training through pilot studies.
Online survey using qualtrics platform. 25 items about camouflaging.; (7 point scale) 21 reasons for (5 point scale), 22 contexts (4 point scale) 21 depression (3 point scale)RAADS(3 point) demographic q's
Focus group, purposive sampling (recruited through self-advocacy group)
Social data from peer reports. Self-report data. One peer was matched to each 1 with ASD. 9 page questionnaires, loneliness q, 24 statements on scale, friendship qualities scale, 23 qs 5 point scale
ESM survey: 20 q's. various responses, yes/no, scales etc. Ipod touch / iphone. 7 times daily
PIEL app on device. 60 mins training. SIAS and SRS-2 (parents of p's under 19 completed). Complete survey 7 times each day for 7 days
ESM Survey. Multiple choice. SRS-2, over 19 self method, under parent method. SIAS - self report. Handheld device and training. 7 times a day 7 days
KIDSCREEN 52q 10 area questionnaire. Adaptive behaviour in 3 areas. Comparison between self-report and parent-report in both questionnaires
Qualitative (semi-structured interview) and thematic analysis. 3 themes in interviews: experiences of learning, experiences of friendships and experiences of bullying
Interpretive Phenomenological Analysis. Interviews conducted - semi structured and started with a open ended statement.
Casual comparative framework. Matched-triad process. Beck Youth Inventories (self report). Semi-structured interviews. Not all p's completed interviews and self report done with researcher in school
Quantitative design. Correlational analysis. Measures used: Social skills improvement system; youth quality of life instrument; self perceptions profile for adolescents
Topic guide; 15 questions for female autism group and 16 for parent group. Based on 3 themes: diagnostic pathway, impact of autism, resilience and coping
Friendship qualities scale. Social responsiveness scale(teachers) Interviews. WASI
Semi structured interviews. Interpretive phenomenological analysis.
Semi structured interviews. 33 questions around 8 areas. Option of face to face or phone interview, or write reflections. 6 wrote, 1 phone.

Intervention	Duration
N/A	N/A
Baseline included 1 meeting an hour weekly (no instructions). Keep log of social activity. Structured social planning (5 areas to focus on). Follow up after intervention.	?
N/A	N/A
N/A	1-2 hrs
Main teacher, parent and TD peer. 3 hours curriculum per week, TD peer twice week	7 months
N/A	N/A
N/A	Not stated
N/A	N/A
N/A	1 week
N/A	N/A
N/A (Interview was assessing an intervention completed as part of a wider study)	Varied
N/A	20 mins
N/A	1 hour
N/A	Not stated
N/A	1 week
N/A	1 week
N/A	1 week
N/A	Not stated
N/A	Not stated
N/A	20-120 mins
N/A	Not stated
N/A	Not stated
N/A	Varied
N/A	2 x approx 30m
N/A	Not stated
N/A	Varied

Key findings
Many individuals with ASD experience anxiety, and interventions to increase social and emotional understanding are beneficial.
Increase social activities and peer interactions, and academic improvement.
Students with ASD have higher levels of behavioural and emotional difficulties at school. High levels of perfectionism, focus on detail. Higher rates of academic under-achievement (54%)
Parental reports suggest less friends and less time with friends than TD. Adolescents don't agree in description. Limited insight into nature of social relations (ASD 70%). No significant differences between ASD and TD on some tasks.
More able to recognise emotional ques, increase positive interactions
HFA interact more with TD peers than ASD, equal understanding of loneliness but more ASD higher levels of loneliness reported
Mixed groups had higher positive social orientation
Potential issues with self report.
Some differences based on SEN category
General agreement in results from both measures. Emphasises positives, and descriptions of school and family as protective and restrictive
Recruiting peers, family involvement typically score higher, meeting peers more medium. Other four even distribution.
Alternating camouflaging = equivalent anxiety/stress. Low camouflage = low stress and anxiety. Main reasons were conventional *higher women, and relational. No differences in depression. Gender and age of diagnosis differs
Clear patterns; enjoy spending time with, have respect, reciprocity. Formal categories secondary to friend. People who understand the friendship with someone with ID will be better friends
No greater levels of loneliness, similar security and conflict to peers. Difference between how others see them and how they see themselves (ASD see more involved than peers)
No significant correlation was between ratings degree of involvement and enjoyment.
cognitively able adolescents/adults were motivated to interact in situations where they felt competent and experienced reciprocity. Also those where they didn't experience significant difficulty.
More likely to spend time at home. Links to cultural differences. Less likely to engage with fewer symptoms. Effects of cultural and gender normals and expectations.
Lowest scores in social support/peers (self and proxy). Some differences between results, parents typically lower scores. Higher adaptive behaviours negatively associated with psychological QoL
1)Motivations to have friends, 2)challenges faced by girls with ASD, 3)masking difficulties. Key focus on masking, and that sometimes parents/teachers will be kept in the dark.
7 key themes:diagnostic issues,being surrounded by boys,experiences of high school,complexity of teen female friendships,puberty, sexual relations/concerns,impact of diagnosis
Anger and disruption measured separately. Challenging behaviour seen in those on the AS may be more closely related to anger rooted in anxiety and frustration
Females with ASD perceive lower social competence, self worth, QoL. Higher internalising and externalising symptoms. Parent indicate higher symptoms = lower social competence.
Data largely cohesive. Reported strategies to mask/camouflage. Negative consequences reported. Difficulties with friendships. All wanted friendships. Positives were also identified.
Teacher report female less social difficulties. ASD females rated similar to non autistic. Females greater social motivation. Females friendships centred on people than actions or objects. Key area of focus being conflict
Feeling unable to fit in due to breaking the rules. Barrier to friendship development. Increased challenges identified in adolescence. Demonstration of various strategies. Negative impact of coping. some develop secondary diagnosis
Utilisation of time alone to distress. Friends seen as important. Qualities similar to TD peers. Positive description of interactions. Difficulties more when bigger group. Conflict as well area of stress. Over apologetic.

Limitations	Implications
Limited review of the literature, and not using outcomes from individuals themselves.	Provide a summary of previous research and also adress some misconceptions.
Small sample size, only one setting. Replicate with a larger variety of symptoms.	Show the usefulness and positive outcomes of the intervention in various aspects. Demonstrated in a small sample so would be useful to extend in future.
All second hand (not listed in article though). Quantative in method, not full IQ tests.	Point to a need for alternative models of support in mainstream classrooms, and help to develop coping strategies.
Small sample. Gender disparity. Focus on high functioning. Lack of generalisability.	Need more research, larger sample, more females. Should consider compensation mechanisms more in research.
No control group, ecological model, limited verbal tasks, teachers aware in study	Promote activities, provides a basis for futher research.
Small sample, limited females	Suggest positive interactions are sought, but don't always know how to achieve these. Useful in designing interventions. Suggestive of further study.
At one time period, not over a longer timescale.	Support inclusion within mainstream settings and also suggest that there are differences to be considered.
Not clear measures are reliable in ASD. Small sample, minority of females.	Contributes to ensuring early support
Only at a single timepoint, single state pps, single measure, parental report	Address planning for participation
Lack of control in small sample, no info about those who didn't want to take part, multiple diagnoses	Provide an indepth view of individuals and allow for their voices to be heard (unlike previous research which proxy reports)
Only individuals able to articulate themselves. Small sample. Varied methods. No record of comorbid diagnoses	Contribute to wider study. Provide areas in which to go forward. Provide empirical grounding to base future research on.
Poorly represented sample.	Links to previous research, possible link between masking and social anxiety needs further research. Add to reasons why camouglage. Inform during diagnosis (clinicians)
Focus group confidence/true beliefs. Limited limitations cited, generally focused upon limits of focus groups.	Gives some ideas of the thoughts and feelings of a specific group of people, show the complexity of the topic and also the presence of concern/though in people with ID
Single time point and in one area. Limited ages, no other disabilities, limited SES and cultural groups	Work toward wider aim of establishing what teachers, children, parents, programs and curricula is best able to promote social integration. Aid understanding of self and others
Difficulty getting p's, excluded sever ASD and ID, interpreting questions may alter views, training on tech needed	Useful to study treatment effectiveness or monitoring changes in symptoms. An alternative way for participation in line with technological advances
No comparison to neurotypical peers. Wide age range. Not matching in both countries, comorbid diagnoses not evaluated	Provide accurate/detailed information to facilitate intervention to enhance social participation of cognitively able adolescents/adults with ASD
Not representative, no comparison to neurotypical peers.	Support the need for interventions that consider the culturally derived heterogeneity of individuals with ASD and address their challenges in social participation
Small sample, methodological tool limitations, only 1 dad response, at a single point in time	Help initiate conversations and be a starting point for interventions
One location, requirment of being able to communicate, female only sample so no comparison	Considerations of things to look for in females, and also provide an insight into possible emerging difficulties or problems. Impact on interventions
Didn't consider prospectives of other family members/those close to individual/very loose structure	Support the need for consideration of gender differences and further research. Document impact and close links to and with mental health
Small sample size. Due to self selection may not be representative of whole population.	Clinical implications for the increase in mental health. Offer support for strategy and interventions. Increase importance of mental health screening in individuals with ASD
Small sample size and various between groups and for specific measures. No parent report for noASD.	Supports and intervention programming. Understanding relationship between social/emotional health and problem behaviours. Direction to building positive self-concept.
Small sample. Inbalance between self and clinical diagnosed participants. Recruitment bias. Inbalance in group sizes	Gained a first hand insight into experiences. Contributes to ongoing evaluations of clinical diagnosis and possible male bias in measurment tools
Small sample size. Non ASD wide range of diagnoses. Hetrogenous sample.	Provide awareness that difficulties may not be noticable. Influence measures of difficulty and their reliability when differences have been identified.
IPA limited generalisation. Self selection. Majority higher functioning. No comparison to males. small sample.	Understandings of possible coping strategies. Uncovering the hidden aspects for females. Contribute to diagnostic evaluation. Consideration for interventions.
Small number of pps. Not got data from females' peers. Cannot guarantee the influence of others in answers.	Aid parents/professionals develop specific and meaningful strategies to assist and negotiate hidden curriculum. Suggest there is an awareness, but need additional support.

Appendix 4

Theme	Subtheme	Article number																									
		1	2	3	4	5	6	7	8	9	#	#	#	#	#	#	#	#	#	#	#	21	22	23	24	25	26
Concepts	Theory of Mind / Executive functioning																										
	Models of disability																										
	Vulnerability																										
Gender	Differences between males and females																										
	Social norms and expectations																										
	Desire and motivation for friendships																										
Social relationships	Social validation																										
	Changes in dynamics within friendships																										
	Self versus proxy report																										
Impacts	Definitions of friendship																										
	Quality of Life / Well-being / Mental health																										
	Isolation / exclusion																										
Social world	Identity / agency / self-esteem / stigma / belonging																										
	Hidden curriculum																										
	Technology / social media																										
Adolescence	Social environment																										
	Solitary activities / free time																										
	Challenges																										
Coping strategies	Transition period / changes in dynamics / critical time																										
	Time out / extra processing time																										
	Social scripting																										
	Camouflaging / masking																										

## Appendix 5

19 sources



*Search selected UK News sources*

### Selected Sources [Clear all](#)

Daily Record and Sunday Mail ✕  
Daily Star ✕  
The Daily Mail and Mail on Sunday (London) ✕  
The Express ✕  
MailOnline ✕  
The Mirror (The Daily Mirror and The Sunday Mirror) ✕

### Popular

UK National Newspapers  
UK National Broadsheets  
UK National Tabloids  
UK Regional Newspapers

19 sources



*Search selected UK News sources*

### Selected Sources [Clear all](#)

The Mirror (The Daily Mirror and The Sunday Mirror) ✕  
The News of the World ✕  
The People ✕  
The Sun (England) ✕  
The Sunday Express ✕  
The Daily Telegraph (London) ✕  
The European ✕  
The Guardian(London) ✕  
The Independent (United Kingdom) ✕  
The Observer(London) ✕  
The Sunday Telegraph (London) ✕  
The Sunday Times (London) ✕  
The Times (London) ✕  
Telegraph.co.uk ✕

### Popular

UK National Newspapers  
UK National Broadsheets  
UK National Tabloids  
UK Regional Newspapers

## Appendix 6

Search term	Initial results (n=)	Removed			Articles screened	Articles removed
Autism	369	331	38	Refinement 1	822	667
Asperger's	69	55	14	Refinement 2	155	57
Asperger's syndrome	48	29	19	Refinement 3	98	73
Autistic	242	197	45	Refinement 4	25	10
Autism Spectrum	28	18	10			
Autistic Spectrum	17	12	5	Further removals	15	4
ASD	12	7	5			
ASC	5	2	3			
Grey literature	32	16	16			
	822	667				
<b>Total results</b>	155	98		<b>Articles included in final analysis</b>	11	
<b>Duplicates</b>	57					
<b>Articles to be screened</b>	98					

**2019**

Search term	Initial results (n=)	Removed			Articles screened	Articles removed
Autism	304	254		Refinement 1	718	546
Asperger's	71	52		Refinement 2 (duplicates)	172	79
Asperger's syndrome	39	25		Refinement 3	93	71
Autistic	223	169		Refinement 4	22	6
Autism Spectrum	21	11				
Autistic Spectrum	26	10		Further removals	16	5
ASD	2	2				
ASC	7	7				
Grey literature	25	16				
	718	546				
<b>Total results</b>	172			<b>Articles included in final analysis</b>	11	
<b>Duplicates</b>	79					
<b>Articles to be screened</b>	93					

**2015**



## Appendix 7

### Bethany Edwards

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**From:** healthethics@bangor.ac.uk  
**Sent:** 03 December 2020 10:41  
**To:** Bethany Edwards  
**Subject:** Ethical approval granted for 2020-16813 The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

Dear Bethany,

2020-16813 The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

Your research proposal number 2020-16813 has been reviewed by the [Pre-Aug 2018] Healthcare Sciences (Post-reg) Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

### Bethany Edwards

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**From:** healthethics@bangor.ac.uk  
**Sent:** 09 February 2021 10:39  
**To:** Bethany Edwards  
**Subject:** Ethical approval granted for 2020-16813-A14739 Amendment to to The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

Dear Bethany,

2020-16813-A14739 Amendment to to The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

Your research proposal number 2020-16813-A14739 has been reviewed by the [Pre-Aug 2018] Healthcare Sciences (Post-reg) Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

## Appendix 8

### Study advertising material

Subject: Stakeholder online workshops – Autism research Bangor University

*Dear (name),*

*I am currently a 3<sup>rd</sup> year PhD Candidate in the School of Health Science, Bangor University. I am wanting to engage with a range of stakeholders to develop a tool for autistic teenage girls to summarise their needs, that can be used across education, health and social settings. This will be done through online workshops.*

*The two stakeholder groups are:*

- Autistic females aged 13 and over.*
- Professionals that are involved with autism (e.g. education, health, social care, policy and governance, researchers and academics, and other individuals such as those in the private or voluntary sector).*

We are wanting to hear from people who meet these criteria:

- Based in Wales (place of work)
- Have access to a device that can be used to participate in workshops.

*I would be grateful if you could share this among your organisation and contacts to anyone that may be interested in taking part.*

I have provided my contact details if you have any questions or require further information about what participating would involve.

Many thanks  
Bethany Edwards

**Email:** [edu4a3@bangor.ac.uk](mailto:edu4a3@bangor.ac.uk)

**Phone:** 01248 383131

Graphic advertising material

## YN EISIAU - CYFRANOGWYR

*Yn angerddol am sicrhau bod merched awtistig yn cael eu cefnogi? Yn ferch awtistig? Yn weithiwr proffesiynol yn y maes hwn? Yna efallai y bydd cymryd rhan yn yr ymchwil hon i chi.*

### Pwy?

- **Merch awtistig** 13 oed neu hŷn
- **Gweithiwr proffesiynol yn y maes** (e.g. *Athro, Seicolegydd, Gweithiwr Cymdeithasol, Cydlynnydd Anghenion Addysgol Arbennig ac Anableddau, Eiriolwr, Mentor, Ymchwilydd, Academaidd, Gweithiwr Iechyd, Lluniwr polisiau ac ati*).

### Beth?

Gweithdai cyd-gynllunio ar-lein gyda'r nod o ddatblygu adnodd yn benodol ar gyfer merched awtistig yn eu harddegau y gellir ei ddefnyddio ar draws lleoliadau addysg, iechyd a gofal cymdeithasol.

### Diddordeb neu a hoffech chi wybod mwy?

Os hoffech gymryd rhan, neu os hoffech ragor o wybodaeth.

### Cysylltwch â:

Bethany Edwards, Myfyriwr PhD, E-bost ([edu4a3@bangor.ac.uk](mailto:edu4a3@bangor.ac.uk))



PRIFYSGOL  
**BANGOR**  
UNIVERSITY

## PARTICIPANTS NEEDED

*Passionate about ensuring autistic girls are supported? Autistic female? Professional in this area? Then taking part in this research may be for you.*

### Who?

- **Autistic female** aged 13 or older
- **Professional in the field** (e.g. *teacher, psychologist, social worker, advocate, mentor, researcher, academic, health worker, policy maker, etc.*).

### What?

Online co-design workshops aiming to develop a tool specifically for autistic teenage girls that can be used across education, health and social care settings.

### Interested or would like to know more?

If you are interested in taking part or would like more information

### Please contact:

Bethany Edwards, PhD Student, Email ([edu4a3@bangor.ac.uk](mailto:edu4a3@bangor.ac.uk))



PRIFYSGOL  
**BANGOR**  
UNIVERSITY

## Appendix 10

*What people appreciate about me? (like and admire.*

IMAGE WOULD GO HERE

*How to support me*

*What's important to me*

## Appendix 11

Group 1	Group 2
<p>Croeso / Welcome</p> <p>This workshop will last about 90 minutes.</p>	<p>Croeso / Welcome</p> <p>This workshop will last about 90 minutes.</p>
<p>Session schedule</p> <p>Introductions to participating and group agreement.</p> <p>Ice breaker activity.</p> <p>Profile activity.</p> <p>BREAK-5 minutes</p> <p>Discussion about key points.</p> <p>Other feedback and comments.</p> <p>Conclusion and explanation about phase 2.</p>	<p>Session schedule</p> <p>Introductions to participating and group agreement.</p> <p>Ice breaker activity.</p> <p>Profile activity.</p> <p>BREAK-5 minutes</p> <p>Discussion about key points.</p> <p>Other feedback and comments.</p> <p>Conclusion and explanation about phase 2.</p>
<p>Group agreement</p> <p>If you must leave at any time mid-workshop, let the researcher know. This is to ensure your safety.</p> <p>Confidentiality / privacy</p> <p>Respectful of others</p> <p>Any other things you want to be included?</p>	<p>Group agreement</p> <p>If you must leave at any time mid-workshop, let the researcher know. This is to ensure your safety.</p> <p>Confidentiality / privacy</p> <p>Respectful of others</p> <p>Any other things you want to be included?</p>
Ice breaker -	Ice breaker -
<p>Case profile activity</p> <p>Use your own personal experiences and how you would approach this if you were completing a one-page profile.</p> <p><i>What people appreciate about me (like and admire)</i></p> <p><i>What's important to me</i></p> <p><i>How to support me</i></p> <p><i>Other comments?</i></p>	<p>Case profile activity</p> <p><b>Charlotte is a quiet, well-behaved 14-year-old girl in a mainstream school and has a diagnosis of autism.</b></p> <ul style="list-style-type: none"> <li>Charlotte has some teaching assistant support for dyslexia and is in the middle sets for all her subjects.</li> <li>She feels as though she is struggling at school and feels isolated.</li> <li>She is permanently anxious about the quality of her work.</li> <li>She is expected to achieve good results and go to university – she just needs more support to access the social world of her peers, to develop the self-confidence to approach the challenges of school life, and to not be missed through her lack of challenging behaviours.</li> <li>She likes to sit at the back of class and doesn't put her hand up or answers questions.</li> </ul>

	<ul style="list-style-type: none"> <li>• Sitting at the back of class allows her to observe her peers and plan her reactions according to what she sees other people doing, she may not work it out on her own.</li> <li>• Her reluctance to answer questions comes from her strong perfectionism, as she does not want to attempt something she might get wrong, and even if she does know the answer, she feels too shy to open herself up to attention from her peers.</li> <li>• She likes to follow rules and a interprets instructions literally.</li> <li>• She can be the last to laugh at a joke, as she waits until she is sure that everyone else is laughing.</li> <li>• She may be quiet, but she is not automatically 'ok'.</li> <li>• Charlotte's best friend is called Jessica.</li> <li>• Charlotte has really enjoyed drama and acting since moving to high school. She appeared good at it so was offered a place at a prestigious youth theatre. This interest has now expanded to include the literature in the drama's she was involved with, so much so, she can recite large sections of her favourite Shakespeare.</li> </ul>
Break – 5 minutes	<p>Which information from it do you view as important?</p> <p><i>What people appreciate about me (like and admire)</i></p> <p><i>What's important to me</i></p> <p><i>How to support me</i></p> <p><i>Other comments?</i></p>
<p>Discussion – activity</p> <p><i>How did you find completing the one-page profile?</i></p> <p><i>What do you think is good about it?</i></p> <p><i>Can anything be improved?</i></p> <p><i>Focusing on autistic females, is it suitable / fit for purpose?</i></p> <p><i>Other comments?</i></p>	Break – 5 minutes
<p>Feedback / comments (open)</p> <p>For example...</p>	Discussion – activity

<p><i>Thoughts about the importance of this study.</i></p> <p><i>Thoughts about the sample group (autistic teenage girls)</i></p> <p><i>Applications in your life?</i></p>	<p><i>How did you find completing the one-page profile?</i></p> <p><i>What do you think is good about it?</i></p> <p><i>Can anything be improved?</i></p> <p><i>Focusing on autistic females, is it suitable / fit for purpose?</i></p> <p><i>Other comments?</i></p>
<p>Next stage</p> <p>This will include both groups taking part in a combined workshop. This will include yourselves and the professional stakeholders.</p> <p>I will get in touch in the next two weeks with suggested dates and times.</p> <p>This second phase will be focused on developing / adapting the current tool.</p>	<p>Feedback / comments (open)</p> <p>For example...</p> <p><i>Thoughts about the importance of this study.</i></p> <p><i>Thoughts about the sample group (autistic teenage girls)</i></p> <p><i>Applications in your life?</i></p>
<p>Do you have any questions?</p> <p>After the workshop, if you have any thoughts or comments that you didn't share, please send them to me by email so that they can be included.</p> <p>Thank you for taking part.</p>	<p>Next stage</p> <p>This will include both groups taking part in a combined workshop. This will include yourselves and autistic people who are taking part.</p> <p>I will get in touch in the next two weeks with suggested dates and times.</p> <p>This second phase will be focused on developing / adapting the current tool.</p>
	<p>Do you have any questions?</p> <p>After the workshop, if you have any thoughts or comments that you didn't share, please send them to me by email so that they can be included.</p> <p>Thank you for taking part.</p>

## Appendix 12

### Summary of tasks for second facilitator for workshops.

Thank you for agreeing to help facilitate my workshop(s). You will be added to the MS Teams calendar invitation.

#### ***Beth's personal contact number for emergencies:***

The PowerPoints are on their which contain the text to be shared in the chat. Any other documents that have been sent to participants can be provided if preferred.

<b>All workshops</b>	<ul style="list-style-type: none"><li>• Note the names of all participants.</li><li>• Introduce yourself, role as facilitator and acting in the background.</li><li>• Monitor chat and verbally highlight to the rest of the group any comments.</li><li>• Admit any participants who may arrive late.</li><li>• Highlight any hands up that the leader of the workshop doesn't appear to notice.</li><li>• Copy and paste information from the slides into the chat throughout the workshop.</li><li>• Contact by phone any participant that suddenly drop out of the workshop (contact details available via OneDrive file).</li><li>• During the break, send workshop leader any comments that may need bringing up later, or any other things to note.</li></ul>
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Workshop 2 – both groups	<ul style="list-style-type: none"> <li>- Note any comments about the researcher's summary of previous stages.</li> <li>- Note any amendments made to the summary of the previous stage before it is accepted.</li> <li>- Lead breakout group for the open discussion of phase 1 and the current tool. Encourage participation. <i>E.g. what information is important to be included on the tool, what features of the current tool are ok, any that could be changed? Are there things that have been missed?</i></li> <li>- After break, share screen with breakout room to create an outline of the structure / basic appearance of the tool (through word and inserting shapes and text boxes).</li> <li>- Save creations.</li> <li>- Re share file with guidance document in the chat.</li> <li>- Make notes during the discussion about the document, where possible, including which area of the document it was in relation to.</li> <li>- Upload any saved files / notes if computerized onto the one drive link provided.</li> </ul>
<b><i>Meet with Beth to discuss notes / themes and gain inter researcher agreement. Agree a summary to be presented at the next stage.</i></b>	
Workshop 3 – both groups	<ul style="list-style-type: none"> <li>- Note comments during the open discussion, as well highlighting those that may need to be explored further later in the workshop.</li> <li>- Make notes regarding the final decisions that are made. Including if there are any conflicting opinions and ideas.</li> </ul>
<b><i>Meet with Beth to discuss notes / themes and any outstanding thoughts to be incorporated into the document.</i></b> <b><i>Share all documents in relation to the study and delete any records from personal computer.</i></b>	

### Structure of data collection – for information

Group 1: Autistic females, family members,

Group 2: Professionals (educational staff, support staff, health care staff, social care professionals, academics, policy makers and advocates).

#### Phase 1 workshop (90 mins) **each group will be conducted separately:**

- Introductions, objectives and 'rules'.
- Ice breaker activity.
- One-page profile activity (personal experience or vignette).
- Conclusion discussion about key points and decisions.
- Summarise scheduling of next phase.

*Researcher prepare some themes and key topics identified in phase 1 to present to all stakeholders.*

Phase 2 workshop (120 mins) *this has the potential to be altered after phase 1* **both groups together:**

- Introductions, objectives and 'rules'.
- Ice breaker activity.
- Feedback of phase 1 presented and open for comments (is this what was meant in phase 1? Has it been interpreted correctly?).
- Breakout groups to discuss tool (including guidance) and then feedback. These will have a facilitator and be a mix of stakeholder groups (they will be matched as closely as possible but due to participant sampling, they may not be exact).
- Further comments and suggestions about changes / amendments to tool (or about any topics that have been discussed).
- Conclusion discussion and scheduling of next phase.

*Researcher to consolidate key comments from workshop to compile some questions to help shape a draft. Also present a summary of topics and areas of conversation to be checked if accurate.*

Phase 3 workshop (60 mins) *this has the potential to be altered after phase 2*, **both groups together:**

- Introductions and objectives.
- Presentation of interpretation of previous phase – open for comments (is this what was meant? Has it been correctly interpreted?).
- Present key questions for participants about design and guidance (this will be designed after phase 2).
- Creation of new tool or amending current tool or guidance.
- Agreement of design and guidance.
- Thanked for taking part.

*Summary sent to all participants (including design and guidance created) along with debriefing information.*

## Appendix 13

**Teitl y prosiect:** Y 'proffil un dudalen' i ferched awtistig yn eu harddegau:  
gwerthuso a datblygu gyda rhanddeiliaid allweddol.  
**Rhif y prosiect:** 2020-16813

**Cyswllt:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



### TAFLEN WYBODAETH I GYFRANWYR

*Annwyl gyfranogwr,*

*Diolch am gytuno i gymryd rhan yn yr astudiaeth hon. Dylai'r llyfryn gwybodaeth hwn roi'r holl wybodaeth sydd ei hangen arnoch i gymryd rhan yn y gweithdai.*

*Mae pob croeso i chi ofyn unrhyw gwestiynau.*

*Llawer o ddiolch*

*Bethany Edwards*

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#### Microsoft Teams

Ar gyfer pob gweithdy, byddwch yn derbyn cyswllt i ymuno â'r cyfarfod Teams i'r cyfeiriad e-bost a ddefnyddiwyd i gysylltu â chi. Dylai hefyd ymddangos ar eich calendr.

Rhai awgrymiadau da ar gyfer defnyddio Teams:

- Defnyddiwch glustffonau pan fyddwch chi ar alwad.
- Mewngofnodwch 5-10 munud cyn yr amser cychwyn rhag ofn y bydd unrhyw broblemau technegol.
- Ymglyfarwyddwch â'r swyddogaeth sgwrsio.
- Trowch y sain i ffwrdd pan nad ydych yn siarad.

Mae Microsoft Teams yn gweithio ar ddyfeisiau symudol a chyfrifiaduron. Cewch osod Teams am ddim ar eich cyfrifiadur. Dylech allu ymuno â'r cyfarfod yn uniongyrchol trwy glicio ar y cyswllt a anfonwyd atoch.

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#### Gwybodaeth am y gweithdai

Byddwch wedi derbyn copi o'r dyluniad proffil Un dudalen cyfredol, yn ogystal â'r canllawiau i'r gweithwyr proffesiynol sy'n ei gwblhau.

Bydd hyn yn ganolog ym mhob cam o'r gweithdai.

---

#### Presenoldeb

Os na allwch fynd i weithdy sydd wedi'i drefnu, rhowch wybod i'r ymchwilydd cyn gynted â phosibl.

Os oes rhaid i chi adael ar unrhyw adeg yng nghanol y gweithdy, rhowch wybod i'r ymchwilydd. Mae hyn er mwyn sicrhau eich diogelwch.

---

#### Cam 1: tua 90 munud

- Cyflwyniadau i gymryd rhan a chytundeb grŵp.
- Gweithgaredd i dorri'r garw (caiff gwybodaeth ei rhannu ar ddiwrnod y gweithdy).
- Gweithgaredd proffil.

**Teitl y prosiect:**Y 'proffil un dudalen' i ferched awtistig yn eu harddegau:  
gwerthuso a datblygu gyda rhanddeiliaid allweddol.  
**Rhif y prosiect:**2020-16813

**Cyswllt:**Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



EGWYL - 5 munud

- Trafodaeth am y pwyntiau allweddol.
- Adborth a sylwadau eraill.
- Casgliad ac esboniad am gam 2.

---

**Cam 2: oddeutu 120 munud (bydd hyn yn cynnwys cyfranogwyr o'r ddau grŵp rhanddeiliaid).**

- Cyflwyniad ac atgoffa am y cytundeb grŵp.
- Torri'r garw.
- Crynodebau Cam 1 a ddarparwyd gan yr ymchwilydd.
- Trafodaeth agored am gam 1 yr offeryn cyfredol.

EGWYL - 10 munud

- Adeiladu teclyn, gan gynnwys sut y bydd yn edrych.
- Trafodaeth am ddogfen ganllaw, beth sydd angen ei gynnwys?
- Casgliad ac esboniad am gam 3.

---

**Cam 3: oddeutu 60 munud (yn yr un modd â cham 2, y ddau grŵp rhanddeiliaid).**

- Cyflwyniad ac amcanion y gweithdy.
- Cyflwyniad yr ymchwilydd o syniadau allweddol Cam 2.
- Sylwadau a thrafodaeth agored.

EGWYL - 15 munud

- Unrhyw benderfyniadau sy'n weddill ynghylch yr offeryn neu'r ddogfen ganllaw.
- Cytundeb ynghylch y dyluniad a'r canllawiau.
- Sylwadau i gloi

---

### **Preifatrwydd**

Yn ystod yr ymchwil hwn, gall pobl dynnu ar brofiadau neu feddyliau personol, ac felly mae'n bwysig cadw'r wybodaeth hon yn breifat.

Felly, disgwylir na fyddwch yn rhannu'r hyn a ddywedir yn ystod y gweithdy nac yn ei drafod mewn unman arall.

---

### **Ôl-gyfarwyddo**

Ar ôl y gweithdy olaf, anfonir crynodeb atoch o themâu'r gweithdy, ynghyd â chopi o unrhyw beth a grëwyd yn ystod y rheini.

## Appendix 14

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



### **PARTICIPANT INFORMATION BOOKLET**

*Dear participant,*

*Thank you for agreeing to take part in this study. This information booklet should give you all the information you need to participate in the workshops.*

*If you have any questions, please ask.*

*Many thanks*

*Bethany Edwards*

---

#### **Microsoft Teams**

For each workshop, you will receive a link to join the Teams meeting to the email address you have been used to be contacted through. It should also appear on your calendar.

Some top tips for using Teams:

- Use headphones when on a call.
- Log on 5-10 minutes before the start time in case of any technical issues.
- Familiarise yourself with the chat function.
- Mute yourself when not speaking.

Microsoft Teams is accessible on both mobile and PC devices. Teams is free to install. You should be able to directly join the meeting by clicking the link sent to you.

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#### **Pre-workshop information**

You will have received a copy of the current One-page profile design, as well as the guidance for professionals completing it.

This will be central within all phases of the workshops.

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#### **Attendance**

If you are unable to attend a scheduled workshop, please let the researcher know as soon as possible.

If you must leave at any time mid-workshop, let the researcher know. This is to ensure your safety.

---

#### **Phase 1: approximately 90 minutes**

- Introductions to participating and group agreement.
- Ice breaker activity (information will be shared on the day of the workshop).
- Profile activity.

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BREAK - 5 minutes

- Discussion about key points.
- Other feedback and comments.
- Conclusion and explanation about phase 2.

---

**Phase 2: approximately 120 minutes (this will consist of participants from both stakeholder groups).**

- Introduction and reminder of group agreement.
- Ice breaker.
- Phase 1 summaries provided by the researcher.
- Open discussion about phase 1 and current tool.

BREAK – 10 minutes

- Construction of a tool, including how it will look.
- Discussion about guidance document, what needs to be included?
- Conclusion and explanation about phase 3.

---

**Phase 3: approximately 60 minutes (similarly to phase 2, both stakeholder groups).**

- Introduction and workshop objectives.
- Researcher presentation of key ideas from Phase 2.
- Comments and open discussion.

BREAK - 5 minutes

- Any outstanding decisions about the tool or guidance document.
- Agreement of design and guidance.
- Concluding remarks.

---

### **Privacy**

During this research, people may draw upon personal experiences or thoughts, it is therefore important to treat this information with privacy.

Therefore, it is expected that you will not share what is said during the workshop or discuss in any other setting.

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### **Debriefing**

After the final workshop, you will be sent a summary of what the themes were from the workshop, as well as a copy of anything created during them.

## Appendix 15

**Teitl y Project:** Y 'proffil un dudalen' i ferched awtistig yn eu harddegau:  
gwerthuso a datblygu gyda rhanddeiliaid allweddol.  
**Rhif Project:** 2020-16813

**Cyswllt:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



### TAFLEN WYBODAETH

Pam y gofynnwyd i chi gymryd rhan:

*Fe'ch gwahoddir i gymryd rhan yn yr ymchwil hon gan ein bod am glywed gan ystod o randdeiliaid i ddatblygu adnodd i ferched awtistig yn eu harddegau i grynhoi eu hanghenion, y gellir ei ddefnyddio ar draws lleoliadau addysg, iechyd a chymdeithasol.*

*Rydym eisiau clywed gan bobl sy'n bodloni'r meini prawf canlynol:*

- *Wedi'u lleoli yng ngogledd Cymru (man gwaith)*
- *Rôl gyfredol neu swydd gyflogedig yn y maes.*
- *Gyda mynediad at ddyfais y gellir ei ddefnyddio i gymryd rhan mewn gweithdai.*

*Gellir cynnwys ystod o swyddi, felly nid yw'r rhestr hon yn gynhwysfawr ond yn syniad o'r sectorau'n fras:*

- *Addysg*
- *Gofal iechyd*
- *Gofal cymdeithasol*
- *Polisi a llywodraethu*
- *Ymchwilwyr ac academyddion*
- *Eraill, e.e. eiriolaeth, gwaith gwirfoddol, y sector preifat, elusennau a Sefydliadau Anllywodraethol.*

Beth yw pwrpas yr astudiaeth hon:

*Mae'r astudiaeth hon yn ymwneud â pha elfennau sy'n bwysig wrth ddarparu crynodeb am unigolyn, yn ogystal â pha rwystrau a chyfyngiadau posibl a allai fod yn eich sector, gydag awgrymiadau yn cael eu gwneud ynghylch eu goresgyn.*

*Rydyn ni eisiau gwybod am eich profiadau a'ch barn er mwyn cyd-gynhyrchu templed a dogfen gryno yn benodol ar gyfer merched awtistig yn eu harddegau.*

*Bydd yr astudiaeth hon hefyd yn galluogi cael trafodaethau rhyngoch chi yn y grŵp 'proffesiynol', yn ogystal â merched awtistig a'u rhieni.*

Cymryd rhan:

*Does dim rhaid i chi gymryd rhan yn yr astudiaeth hon os yw'n well gennych beidio.*

Yr hyn fydd yn digwydd yn yr astudiaeth:

*Bydd yr astudiaeth hon yn golygu eich bod chi'n cymryd rhan mewn gweithdai. Byddant yn cynnwys trafodaethau â rhanddeiliaid eraill a datblygu'r adnodd i'w ddefnyddio.*



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gwerthuso a datblygu gyda rhanddeiliaid allweddol.  
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**Cyswllt:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



- *Bydd Cam 1 yn cynnwys gweithdy gyda rhanddeiliaid eraill a ystyrir yn weithwyr proffesiynol, gan ddefnyddio astudiaeth achos i archwilio'r adnodd cyfredol sydd ar gael (dim mwy na 90 munud)*
- *Bydd Cam 2 yn cynnwys gweithdy ynghyd â'r holl rhanddeiliaid, gan archwilio canfyddiadau'r cam cyntaf, ynghyd â datblygu'r adnodd mewn ymateb i sylwadau ac adborth (120 munud ar y mwyaf)*
- *Bydd Cam 3 unwaith eto yn cynnwys gweithdy gyda'r holl rhanddeiliaid er mwyn gwneud y newidiadau terfynol i'r adnodd a'r canllawiau (60 munud ar y mwyaf) a chytuno arnynt.*

*Gallwch chi gymryd rhan mewn cymaint o'r camau ag y dymunwch, ond rydyn ni'n eich annog chi i gymryd rhan ynddynt i gyd i gael y canlyniad gorau posib o'r astudiaeth hon.*

#### Cyfrinachedd

*Bydd yr holl wybodaeth a gesglir amdanoch yn ystod yr ymchwil yn cael ei chadw'n gyfrinachol.*

*Bydd unrhyw wybodaeth a ddefnyddir yn ddiweddarach i adrodd ar y canlyniadau yn cael ei gwneud yn anhysbys fel na fydd modd eich adnabod. Ni fydd modd eich adnabod mewn unrhyw adroddiadau neu gyhoeddiadau dilynol.*

*Pe baech yn datgelu neu'n ein hysbysu y gallech chi, neu rywun arall fod mewn perygl sylweddol o niwed, efallai y bydd rhaid hysbysu asiantaethau perthnasol. Os yw hynny'n briodol ac yn bosib, byddai hyn yn cael ei egluro yn gyntaf.*

Beth fydd yn digwydd i'r canlyniadau:

*Gellir rhannu'r templed cryno a grëwyd erbyn diwedd y gweithdai ag unigolion eraill, gan gynnwys gweithwyr proffesiynol fel chi, i'w helpu i'w ddefnyddio i gefnogi pobl awtistig. Ni fydd hyn yn cynnwys disgrifiadau o'r rhai sy'n ymwneud ag ef yn cael eu gwneud, dim ond gwybodaeth am y project a'r tîm ymchwil.*

*Bydd y canfyddiadau yn cael eu cynnwys yn fy nhraethawd PhD, fel y gellir eu cynnwys mewn cyflwyniadau academaidd a chyhoeddiadau yn y dyfodol. Bydd y data'n cael eu cadw'n ddiogel, a bydd unrhyw fanylion o'r hyn y gellir adnabod rhywun yn cael eu tynnu o'r wybodaeth sydd wedi'i chynnwys yn unrhyw un o'r cynhyrchion uchod fel na ellir eich adnabod.*

Gwybodaeth am y gweithdai:

*Bydd gweithdai yn cael eu cynnal gan ddefnyddio Microsoft Teams. Ar ôl i chi gydsynio i gymryd rhan, byddwn yn trefnu amser cyfleus i gyfranogwyr gynnal y gweithdy.*

*Anfonir gwybodaeth a manylion wedyn, gan gynnwys cyswllt i'r gweithdy.*

Beth yw manteision cymryd rhan?

*Er nad oes dim manteision ariannol i gymryd rhan, y gobaith yw y bydd yr ymchwil hwn yn codi ymwybyddiaeth o brofiadau merched yn eu harddegau sydd â chyflyrau ar y sbectrwm awtistiaeth. Yn ogystal, y gobaith yw y bydd yr adnodd a ddatblygir yn ddefnyddiol ac y bydd ganddo botensial i'w ddefnyddio.*



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**Cyswllt:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



*Mae cymryd rhan ochr yn ochr â rhanddeiliaid eraill yn debygol o roi safbwyntiau amrywiol i chi a all ddylanwadu ar eich arfer yn y dyfodol.*

**Beth yw'r risgiau o gymryd rhan?**

*Nid oes unrhyw risgiau ymddangosiadol o gymryd rhan, gan nad yw'r pynciau'n debygol o fod yn sensitif. Fodd bynnag, os ydych chi'n teimlo'n ofidus o gwbl, gallwch gysylltu â'r ymchwilydd neu'r tîm ymchwil.*

*Mae asesiad risg llawn wedi'i gwblhau.*

**Yr hawl i dynnu'n ôl**

*Mae gennych hawl i dynnu eich cydsyniad yn ôl ac unrhyw ddata a gasglwyd ar unrhyw adeg yn ystod yr astudiaeth. Ar ôl i'ch cyfranogiad ddod i ben ac ar ôl i'r data gael ei wneud yn ddienw, ni fydd modd tynnu data'n ôl o'r astudiaeth.*

**Recordio**

*Bydd gweithdai'n cael eu recordio i sicrhau bod y trafodaethau'n cael eu trawsgrifio a'u dehongli'n gywir. Caiff yr holl recordiadau sain eu storio ar ddyfais sydd wedi ei hamgryptio a dim ond y tîm ymchwil fydd yn cael eu clywed. Cânt eu dinistrio ar ôl pum mlynedd.*

**Cymeradwyo'r astudiaeth**

*Cafodd yr astudiaeth ei chymeradwyo gan Bwyllgor Moeseg Academiaidd y Gwyddorau Gofal Iechyd a Meddygol (2020-16813)*

**Cysylltu ynglŷn ag unrhyw bryderon**

*Os oes gennych unrhyw gwynion am yr astudiaeth hon, cysylltwch â:*

- Dr Jaci Huws (Goruchwyliwr y Project) - [j.huws@bangor.ac.uk](mailto:j.huws@bangor.ac.uk)
- Dr Anne-Marie Smith (Goruchwyliwr y Project) - [amsmith@bangor.ac.uk](mailto:amsmith@bangor.ac.uk)
- Dr Lynne Williams (Pennaeth yr Ysgol) - [lynne.williams@bangor.ac.uk](mailto:lynne.williams@bangor.ac.uk)

**Unrhyw gwestiynau?**

*Mae pob croeso i chi ofyn unrhyw gwestiynau i ni. Ni ddylech lofnodi'r ffurflen gydsynio i gymryd rhan yn yr astudiaeth os nad ydych wedi cael ateb i'ch cwestiynau i gyd neu os oes gennych unrhyw amheuan.*

## Appendix 16

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



### INFORMATION SHEET

Why you have been asked to participate:

*You are invited to take part in this research as we want to hear from a range of stakeholders to develop a tool for autistic teenage girls to summarise their needs which can be used across education, health and social settings.*

*We are wanting to hear from people who meet these criteria:*

- *Based in Wales (place of work)*
- *Current role or employment in the field.*
- *Have access to a device that can be used to participate in workshops.*

*There are a range of job roles that may be included, so this list is not exhaustive but an indication of the broad sectors:*

- *Education*
- *Health Care*
- *Social Care*
- *Policy and governance*
- *Researchers and academics*
- *Other, e.g. advocacy, voluntary work, private sector, charities and Non-Governmental Organisations.*

What this study is about:

*This study is about what elements are important when providing a summary about an individual, as well as what potential barriers and limitations may present in your sector, with suggestions made about overcoming them.*

*We want to know about your experiences and opinions in order to co-produce a template and summary document specifically for autistic teenage girls.*

*This study will also allow for discussions between yourself in the 'professional' group, as well as autistic females and their parents.*

Taking part:

*You do not have to take part in this study if you would not like to.*

What this study involves:

*This study will involve you taking part in workshops. They will involve discussions with other stakeholders and developing the tool to be used.*

- *Phase 1 will involve a workshop with other stakeholders considered professionals, utilising a case study to explore the current tool that is available (maximum 90 minutes)*
- *Phase 2 will involve a workshop along with all stakeholders, exploring the findings from the first phase, as well as developing the tool in response to comments and feedback (maximum 120 minutes)*

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- *Phase 3 will again involve a workshop with all stakeholders in order to make the final changes to, and agree the tool and guidance document (maximum 60 minutes).*

*You are able to take part in as many of the phases as you like, however we encourage you to take part in them all to get the best possible outcome from this study.*

#### Confidentiality

*All information which is collected about you during the research will be kept confidential.*

*Any information which is later used in reporting of the results will be anonymised and therefore you will not be recognised. Any subsequent references in reports or publication will not identify.*

*Should you disclose or inform us that you, or someone else might be in significant danger of harm, relevant agencies may need to be informed. Where appropriate and if possible, this would be explained first.*

#### What will happen to the results:

*The summary template created by the end of the workshops may be shared with other individuals, including professionals like yourself, to help them use it to support autistic people. This will not include descriptions of those involved in it being made, only the project information and the research team.*

*The findings will be included in my PhD thesis, as may be included in academic presentations and publications in the future. The data will be stored securely, and any information included in any of the above outputs will be anonymised so that you cannot be identified.*

#### Workshop information

*Workshops will be conducted using Microsoft Teams. Once you have consented to take part, we will arrange with participants a most convenient time to run the workshop.*

*Information and details will then be sent, including a link to the workshop.*

#### What are the benefits of taking part?

*Whilst there are no financial incentives to take part, it is hoped that this research will raise awareness of the experiences of teenage girls with Autism Spectrum Conditions. In addition, it is hoped that the tool developed will be useful and have potential to be used.*

*Taking part alongside other stakeholders is likely to give you varying perspectives which can influence your future practice.*

#### What are the risks of taking part?

*There are no perceived risks to taking part, as the topics are not likely to be sensitive. However, if you do experience any distress, you can contact the researcher or research team.*

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, [edu4a3@bangor.ac.uk](mailto:edu4a3@bangor.ac.uk), 01248 383131



*A full risk assessment has been completed.*

#### Right to withdraw

*You have the right to withdraw your consent and any collected data at any time during the study. Once participation has been completed and data anonymised, data will be unable to be withdrawn from the study.*

#### Recording

*Workshops will be recorded to ensure accurate transcription and interpretation of the discussions. All audio recordings will be stored on an encrypted device accessible only to the research team. They will be destroyed after five years.*

#### Study approval

*This study has been approved by Healthcare and Medical Sciences Academic Ethics Committee (2020-16813)*

#### Contact with any concerns

*If you have any concerns about how this study is conducted, please contact:*

- Dr Jaci Huws (Project Supervisor) – [j.huws@bangor.ac.uk](mailto:j.huws@bangor.ac.uk)
- Dr Anne-Marie Smith (Project Supervisor) – [amsmith@bangor.ac.uk](mailto:amsmith@bangor.ac.uk)
- Dr Lynne Williams (Head of School) – [Lynne.williams@bangor.ac.uk](mailto:Lynne.williams@bangor.ac.uk)

#### Any questions?

*Please ask us if you have any questions. You should not sign the consent form consenting to take part in the study if you still have unanswered questions or any doubts.*



## Appendix 17

**Teitl y Project:** Y 'proffil un dudalen' i ferched awtistig yn eu harddegau: gwerthuso a datblygu gyda rhanddeiliaid allweddol.

**Rhif y project:**2020-16813

**Cyswllt:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



### TAFLEN WYBODAETH:

Pam y gofynnwyd i chi gymryd rhan:

*Fe'ch gwahoddir i gymryd rhan yn yr ymchwil hon gan fod gennych ferch 13 oed neu hŷn gyda diagnosis o awtistiaeth (defnyddir y term awtistiaeth ond mae'n cynnwys yr holl dermau diagnostig cysylltiedig).*

*Rydym eisiau clywed gan bobl sy'n bodloni'r meini prawf canlynol:*

- Yn byw yng Cymru
- Gyda merch â diagnosis o awtistiaeth sy'n 13 oed neu'n hŷn
- Gyda mynediad at ddyfais i'ch merch ei defnyddio wrth gymryd rhan mewn gweithdai.

Beth yw pwrpas yr astudiaeth hon:

*Mae'r astudiaeth hon yn ymwneud â'r hyn sy'n bwysig ei gynnwys ar grynodedb am unigolyn ar draws lleoliadau addysg, iechyd a chymdeithasol. Mae hefyd yn cynnwys ystyried ei strwythur yn ogystal â'r arweiniad i weithwyr proffesiynol er mwyn ei ddefnyddio.*

*Nod yr astudiaeth hon yw canolbwyntio'r adnodd hwn ar anghenion merched awtistig trwy gydgyhyrchu trwy ystod o randdeiliaid, gyda phob un yn cael ei ystyried yn gyfartal.*

Cymryd rhan:

*Does dim rhaid i chi gymryd rhan yn yr astudiaeth hon os yw'n well gennych beidio.*

Yr hyn fydd yn digwydd yn yr astudiaeth:

*Mae'r astudiaeth hon yn cynnwys gweithdai trwy Microsoft Teams, lle gall eich merch gyfrannu at drafodaethau, a all fod trwy siarad neu deipio yn y rhan sgwrsio (chat).*

- Bydd gweithdy Cam 1 yn cynnwys cyfranogwyr sydd â diagnosis o awtistiaeth, yn trafod y proffil un dudalen gyfredol, a pha wybodaeth y byddent yn ei chynnwys pe byddai'n cael ei chyflwyno iddynt (90 munud ar y mwyaf)
- Bydd gweithdy Cam 2 yn cynnwys yr holl randdeiliaid, gan drafod canfyddiadau'r cam cyntaf. Gall hyn gynnwys grwpiau sy'n rhannu'n grwpiau llai er mwyn cael trafodaeth bellach. Bydd y cam hwn yn gweithio tuag at symud yr adnodd yn ei flaen, a nodi rhai o safbwyntiau allweddol y grŵp (dim mwy na 120 munud)
- Bydd gweithdy Cam 3 yn cynnwys y penderfyniadau terfynol a'r diwygiadau i'r adnodd, ynghyd â chytundeb rhwng yr holl gyfranogwyr (dim mwy na 60 munud).

Preifatrwydd:

*Bydd yr holl wybodaeth a gesglir amdanoch yn ystod yr ymchwil yn cael ei chadw'n gyfrinachol.*

**Teitl y Project:** Y 'proffil un dudalen' i ferched awtistig yn eu harddegau:  
gwerthuso a datblygu gyda rhanddeiliaid allweddol.  
**Rhif y project:**2020-16813

**Cyswllt:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



*Bydd unrhyw wybodaeth a ddefnyddir yn ddiweddarach i adrodd ar y canlyniadau yn cael ei gwneud yn anhysbys fel na fydd modd eich adnabod. Ni fydd modd eich adnabod mewn unrhyw adroddiadau neu gyhoeddiadau dilynol.*

*Pe bai eich merch yn datgelu neu'n ein hysbysu y gallent hwy, neu rywun arall fod mewn perygl sylweddol o niwed, efallai y bydd rhaid hysbysu asiantaethau perthnasol. Os yw hynny'n briodol ac yn bosib, byddai hyn yn cael ei egluro yn gyntaf.*

**Beth fydd yn digwydd i'r canlyniadau?**

*Gellir rhannu'r templed cryno a fydd wedi'i greu erbyn diwedd y gweithdai â phobl eraill, i'w helpu i ddeall sut y gallant ei ddefnyddio i gefnogi pobl awtistig. Ni fyddant yn gwybod pwy a'i gwnaeth, na bod eich merch wedi cymryd rhan.*

*Bydd y canfyddiadau yn cael eu cynnwys yn fy nhraethawd PhD, ac o bosib mewn cyflwyniadau a chyhoeddiadau academiaidd yn y dyfodol. Bydd y data'n cael eu cadw'n ddiogel, a bydd unrhyw fanylion o'r hyn y gellir adnabod rhywun yn cael eu tynnu o'r wybodaeth sydd wedi'i chynnwys yn unrhyw un o'r uchod fel na ellir eich adnabod chi na'ch merch.*

**Gwybodaeth am y gweithdai**

*Bydd gweithdai yn cael eu cynnal gan ddefnyddio Microsoft Teams. Ar ôl i chi gydsynio i gymryd rhan, byddwn yn trefnu amser cyfleus i gyfranogwyr gynnal y gweithdy. Bydd gan eich merch y dewis ar y diwrnod i gymryd rhan ai peidio.*

*Anfonir gwybodaeth a manylion atoch chi, gan gynnwys cyswllt i'r gweithdy.*

**Beth yw manteision cymryd rhan?**

*Er nad oes dim manteision ariannol i gymryd rhan, y gobaith yw y bydd yr ymchwil hwn yn codi ymwybyddiaeth o brofiadau merched yn eu harddegau sydd â chyflyrau ar y sbectrwm awtistiaeth. Yn ogystal, y gobaith yw y bydd yr adnodd a ddatblygir yn ddefnyddiol ac y bydd ganddo botensial i'w ddefnyddio.*

*Rydym am sicrhau bod profiadau bywyd go iawn yn dylanwadu ar yr astudiaeth, yn ogystal â sicrhau bod pobl awtistig yn cymryd rhan fel partneriaid cyfartal â gweithwyr proffesiynol.*

**Beth yw'r risgiau o gymryd rhan?**

*Nid oes unrhyw risgiau ymddangosiadol o gymryd rhan, gan nad yw'r pynciau'n debygol o fod yn sensitif. Fodd bynnag, os ydych chi neu eich merch yn teimlo'n ofidus o gwbl, gallwch gysylltu â'r ymchwilydd neu'r tîm ymchwil.*

*Mae asesiad risg llawn wedi'i gwblhau.*

**Teitl y Project:** Y 'proffil un dudalen' i ferched awtistig yn eu harddegau: gwerthuso a datblygu gyda rhanddeiliaid allweddol.  
**Rhif y project:**2020-16813

**Cyswllt:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



Yr hawl i dynnu'n ôl

*Mae gennych hawl i dynnu eich cydsyniad chi, a chydsyniad eich merch, yn ôl, ac unrhyw ddata a gasglwyd ar unrhyw adeg yn ystod yr astudiaeth. Ar ôl i'ch cyfranogiad ddod i ben ac ar ôl i'r data gael ei wneud yn ddienw, ni fydd modd tynnu data'n ôl o'r astudiaeth.*

*Bydd eich merch hefyd yn gallu dewis cymryd rhan yn y gweithdai ai peidio, yn ogystal â faint mae hi am gyfrannu at drafodaethau.*

Recordio

*Bydd gweithdai'n cael eu recordio i sicrhau bod y trafodaethau'n cael eu trawsgrifio a'u dehongli'n gywir. Caiff yr holl recordiadau sain eu storio ar ddyfais sydd wedi ei hamgryptio a dim ond y tîm ymchwil fydd yn cael eu clywed. Cânt eu dinistrio ar ôl pum mlynedd.*

Cymeradwyo'r astudiaeth

*Cafodd yr astudiaeth ei chymeradwyo gan Bwyllgor Moeseg Academiaidd y Gwyddorau Gofal Iechyd a Meddygol (2020-16813)*

Cysylltu ynglŷn ag unrhyw bryderon

*Os oes gennych unrhyw gwynion am yr astudiaeth hon, cysylltwch â:*

- Dr Jaci Huws (Goruchwyliwr y Project) - [j.huws@bangor.ac.uk](mailto:j.huws@bangor.ac.uk)
- Dr Anne-Marie Smith (Goruchwyliwr y Project) - [amsmith@bangor.ac.uk](mailto:amsmith@bangor.ac.uk)
- Dr Lynne Williams (Pennaeth yr Ysgol) - [Lynne.williams@bangor.ac.uk](mailto:Lynne.williams@bangor.ac.uk)

Unrhyw gwestiynau?

*Mae pob croeso i chi ein holi os oes gennych chi neu eich merch unrhyw gwestiynau. Ni ddylech lofnodi'r ffurflen gydsynio i gymryd rhan yn yr astudiaeth os nad ydych wedi cael ateb i'ch cwestiynau i gyd neu os oes gennych unrhyw amheuan.*

## Appendix 18

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



### INFORMATION SHEET

Why you have been asked to participate:

*You are invited to take part in this research as you have a daughter aged 13 or over with a diagnosis of autism (the term autism is used but encompasses all related diagnostic terms).*

*We are wanting to hear from people who meet these criteria:*

- *Living in Wales*
- *Have a daughter with an autism diagnosis aged 13 or over*
- *Access to a device for your daughter to use when participating in workshops.*

What this study is about:

*This study is about what is important to include on a summary of an individual across education, health and social settings. It also includes considering its structure as well as the guidance for professionals in order to utilise it.*

*This study aims to focus this tool on the needs of autistic females through coproduction through a range of stakeholders, with each being viewed as equals.*

Taking part:

*You do not have to take part in this study if you would not like to.*

What this study involves:

*This study involves workshops through Microsoft Teams, where your daughter can contribute to discussions, which can through speaking or typing in the chat function.*

- *Phase 1 workshop will include participants with an autism diagnosis, discussing the current one-page profile, and what information they would include if they were presented with it (maximum 90 minutes)*
- *Phase 2 workshop will include all stakeholders, discussing the findings from the first phase. This may include break out groups to enable further discussion. This stage will work towards progressing the tool and identifying some of the key viewpoints of the group (maximum 120 minutes)*
- *Phase 3 workshop will involve the final decisions and amendments to the tool as well as an agreement between all participants (maximum 60 minutes).*

Privacy:

*All information which is collected about you during the research will be kept confidential.*

*Any information which is later used in reporting of the results will be anonymised and therefore you will not be recognised. Any subsequent references in reports or publication will not identify.*



**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



*Should your daughter disclose or inform us that they, or someone else might be in significant danger of harm, relevant agencies may need to be informed. Where appropriate and if possible, this would be explained first.*

**What will happen to the results?**

*The summary template created by the end of the workshops may be shared with other people to help them understand how they can use it to support autistic people. They will not know who made it or that your daughter was involved.*

*The findings will be included in my PhD thesis, as may be included in academic presentations and publications in the future. The data will be stored securely, and any information included in any of the above will be anonymised so that you and your daughter cannot be identified.*

**Workshop information**

*Workshops will be conducted using Microsoft Teams. Once you have consented to take part, we will arrange with participants a most convenient time to run the workshop. Your daughter will have the choice on the day to take part or not.*

*Information and details will be sent to you, including a link to the workshop.*

**What are the benefits of taking part?**

*Whilst there are no financial incentives to take part, it is hoped that this research will raise awareness of the experiences of teenage girls with Autism Spectrum Conditions. In addition, it is hoped that the tool developed will be useful and have potential to be used.*

*We want to ensure real life experiences influence the study, as well as ensuring autistic people are involved as equal partners with professionals.*

**What are the risks of taking part?**

*There are no perceived risks to taking part, as the topics are not likely to be sensitive. However, if you, or your daughter do experience any distress, you can contact the researcher or research team.*

*A full risk assessment has been completed.*

**Right to withdraw**

*You have the right to withdraw your, and your daughters' consent and any collected data at any time during the study. Once participation has been completed and data anonymised, data will be unable to be withdrawn from the study.*

*Your daughter will also be able to choose whether to take part in the workshops, as well as how much she wants to contribute to discussions.*

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, [edu4a3@bangor.ac.uk](mailto:edu4a3@bangor.ac.uk), 01248 383131



#### Recording

*Workshops will be recorded to ensure accurate transcription and interpretation of the discussions. All audio recordings will be stored on an encrypted device accessible only to the research team. They will be destroyed after five years.*

#### Study approval

*This study has been approved by Healthcare and Medical Sciences Academic Ethics Committee (2020-16813)*

#### Contact with any concerns

*If you have any concerns about how this study is conducted, please contact:*

- Dr Jaci Huws (Project Supervisor) – [j.huws@bangor.ac.uk](mailto:j.huws@bangor.ac.uk)
- Dr Anne-Marie Smith (Project Supervisor) – [amsmith@bangor.ac.uk](mailto:amsmith@bangor.ac.uk)
- Dr Lynne Williams (Head of School) – [Lynne.williams@bangor.ac.uk](mailto:Lynne.williams@bangor.ac.uk)

#### Any questions?

*Please ask us if you, or your daughter have any questions. You should not sign the consent form consenting to take part in the study if you still have unanswered questions or any doubts.*

## Appendix 19

**Teitl y project:** Y 'proffil un dudalen' i ferched awtistig yn eu harddegau:  
gwerthuso a datblygu gyda rhanddeiliaid allweddol.  
**Rhif y project:** 2020-16813

**Cyswllt:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



### TAFLEN WYBODAETH:

Pam gofynnwyd i chi gymryd rhan

*Fe'ch gwahoddir i gymryd rhan yn yr ymchwil hon gan eich bod rhwng 13 a 18 oed ac yn awtistig.*

*Rydyn ni eisiau clywed gan bobl fel chi*

- *Yn byw yng Cymru*
- *Yn ferch 13 oed neu'n hŷn*
- *Gyda mynediad at ddyfais i chi ei defnyddio wrth gymryd rhan mewn gweithdai.*

Pwrpas yr astudiaeth hon:

*Mae'r astudiaeth hon yn ymwneud â'r hyn sy'n bwysig ei gynnwys ar grynoded o'r hyn sy'n bwysig i bobl mewn swyddi amrywiol wybod amdanoch chi.*

*Byddwn yn canolbwyntio'r adnodd hwn ar eich anghenion, gyda'ch barn yn bwysig iawn i ni. Rydym am eich cynnwys fel nad ydym yn dibynnu ar weithwyr proffesiynol ac oedolion.*

Cymryd rhan:

*Does dim rhaid i chi gymryd rhan yn yr astudiaeth hon os yw'n well gennych beidio.*

Yr hyn fydd yn digwydd yn yr astudiaeth:

*Mae'r astudiaeth hon yn cynnwys gweithdai trwy Microsoft Teams, lle byddwch chi'n cymryd rhan mewn trafodaethau. Gallwch chi siarad neu deipio'ch sylwadau, beth bynnag rydych chi'n teimlo y gallwch chi ei wneud*

- *Bydd gweithdy Cam 1 yn cynnwys pobl fel chi eich hun, yn trafod yr hyn sydd ar gael ar hyn o bryd, a sut y bydddech chi'n ei lenwi. Ni fydd unrhyw weithwyr proffesiynol yn y gweithdy hwn, a fydd, gobeithio, yn gwneud i chi deimlo'n fwy cyfforddus. Gall eich rhiant fod gyda chi pe bai hynny'n eich helpu i gymryd rhan (dim mwy na 90 munud).*
- *Bydd gweithdy Cam 2 yn cynnwys pawb yn yr astudiaeth, lle byddwn yn siarad am y pethau allweddol o gam 1, a gwirio ein bod wedi deall yn iawn. Efallai y byddwn yn rhannu'r grŵp hwn fel y gallwch siarad â llai o bobl. Byddwn yn gweithio tuag at greu'r adnodd, a meddwl am unrhyw benderfyniadau y mae'n rhaid i ni eu gwneud (dim mwy na 120 munud).*
- *Yn y gweithdy cam 3 byddwn yn gwneud penderfyniadau terfynol am yr adnodd, ac yn cytuno bod pawb yn hapus ag ef (60 munud ar y mwyaf)*

*Byddwn yn trefnu amser y gweithdai gyda'ch rhiant/ gwarcheidwad.*

*Gallwch ddewis p'un ai i gymryd rhan yn y gweithdai, yn ogystal â faint rydych chi'n ei ddweud.*

**Teitl y project:** Y 'proffil un dudalen' i ferched awtistig yn eu harddegau:  
gwerthuso a datblygu gyda rhanddeiliaid allweddol.  
**Rhif y project:** 2020-16813

**Cyswllt:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



**Preifatrwydd:**

*Os byddwch yn cymryd rhan, byddwn yn sicrhau na ddefnyddir eich enw, a chaiff unrhyw wybodaeth y gellir eich adnabod ynddi ei thynnu o'r adroddiad.*

*Mae'ch rhiant/gwarcheidwad wedi cael gwybod am yr astudiaeth a'r hyn rydym yn ei wneud er mwyn i chi allu siarad â hwy amdano. Ni fyddant yn gwybod beth rydych yn ei ddweud yn y cyfarfodydd a'r gweithdai ac ni fyddant yn clywed unrhyw recordiadau. Os yw'n well gennych iddynt ddod i'r gweithdy cyntaf, byddant yn clywed yr hyn a ddywedwch.*

*Os dywedwch wrthym y gallech chi, neu rywun rydych yn ei adnabod, fod mewn perygl o gael eich anafu, efallai y bydd rhaid inni gael help gan weithwyr proffesiynol eraill. Byddwn yn gwneud ein gorau i siarad â chi ac egluro beth sy'n digwydd os gwnawn ni hyn.*

**Beth fydd yn digwydd i'r canlyniadau?**

*Gellir rhannu'r templed cryno a fydd wedi'i greu erbyn diwedd y gweithdai â phobl eraill, i'w helpu i ddeall sut y gallant ei ddefnyddio i gefnogi pobl awtistig. Ni fyddant yn gwybod pwy a'i gwnaeth, na'ch bod wedi cymryd rhan.*

*Bydd y canfyddiadau'n cael eu cynnwys yn fy nhraethawd PhD, a gellir eu crybwyll mewn cyflwyniadau eraill neu mewn gwaith yn y dyfodol.*

**Gwybodaeth am y gweithdai**

*Gallwch ddewis ar y diwrnod i gymryd rhan ai peidio.*

*Anfonir gwybodaeth a manylion atoch mewn digon o amser i sicrhau eich bod yn gwybod beth i'w wneud.*

*Cewch ddefnyddio gliniadur/ tabled ffôn i gael mynediad at hwnnw.*

**Recordio:**

*Byddwn yn recordio ein sgysiau er mwyn sicrhau ein bod yn cofio'r hyn rydych yn ei ddweud wrthym. Dim ond y bobl sy'n gwneud yr ymchwil, neb arall, fydd yn cael clywed y recordiadau.*

**Cwestiynau:**

*Mae pob croeso i chi ofyn unrhyw gwestiynau. Cewch ofyn cwestiynau ar unrhyw adeg cyn yr astudiaeth, yn ystod yr astudiaeth ac ar ôl i'r astudiaeth ddod i ben.*



## Appendix 20

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



### INFORMATION SHEET

Why you have been asked to participate:

*You are invited to take part in this research as you are aged between 13- and 18-years and are autistic.*

*We are wanting to hear from people like yourself*

- *Living in Wales*
- *Female aged 13 or over*
- *Access to a device for you to use when participating in workshops.*

What this study is about:

*This study is about what is important to include on a summary of what is important for people in various jobs to know about you.*

*We will to focus this tool on your needs, with your opinions and views being very important to us. We want to involve you so that we don't rely on professionals and adults.*

Taking part:

*You do not have to take part in this study if you would not like to.*

What this study involves:

*This study involves workshops through Microsoft Teams, where you take part in discussions. You can speak or type your comments, whatever you feel able to do,*

- *Phase 1 workshop will include people like yourself, discussing what currently exists and how you would fill it out. No professionals will be within this workshop, which will hopefully make you feel more comfortable. Your parent can be with you if that would help you take part (maximum 90 minutes).*
- *Phase 2 workshop will include everyone in the study, where we will talk about the key things from the 1<sup>st</sup> phase and check that we have understood properly. We may split this group so that you can talk with fewer people. We will work towards making the tool and thinking about any decisions that we must make (maximum 120 minutes).*
- *In the phase 3 workshop we will make final decisions about the tool and agree that everyone is happy with it (maximum 60 minutes)*

*We will sort the time of the workshops with your parent / guardian.*

*You can choose whether to take part in the workshops, as well as how much you say.*

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131

**Privacy:**



*If you take part, we will make sure that your name is not used, and anything that may mean you can be recognised will be taken out of the report.*

*Your parent/career knows about the study and what we are doing so you can talk to them about it. They don't know what you say in the meetings and workshops and will not hear any recordings. If you prefer for them to come to the first workshop, they will hear what you say.*

*If you tell us that you, or someone you know, may be in danger of being hurt, we might have to get help from other professionals. We will try our best to talk to you and explain what is happening if we do this.*

**What will happen to the results?**

*The summary template created by the end of the workshops may be shared with other people to help them understand how they can use it to support autistic people. They will not know who made it or that you were involved.*

*The findings will be included in my PhD writing, and may be mentioned in other presentations or future work.*

**Workshop information**

*You can choose on the day to take part or not.*

*Information and details will be sent to you in plenty of time to make sure you know what to do.*

*You can use a laptop / tablet / phone to access this.*

**Recording:**

*So we can make sure we remember what you tell us, we will record our conversations. This will only be heard by the people who are doing the researching, no one else.*

**Questions:**

*Please ask if you have any questions. You can ask at any time before, during and after the study has finished.*

## Appendix 21

**Teitl y project:** Y 'proffil un dudalen' i ferched awtistig yn eu harddegau:  
gwerthuso a datblygu gyda rhanddeiliaid allweddol.  
**Rhif project:** 2020-16813

**Cyswllt:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



### TAFLEN WYBODAETH

Pam y gofynnwyd i chi gymryd rhan

*Fe'ch gwahoddir i gymryd rhan yn yr ymchwil hon gan eich bod yn 13 oed neu'n hŷn gyda diagnosis o awtistiaeth (defnyddir y term awtistiaeth ond mae'n cwmpasu'r holl dermau diagnostig cysylltiedig).*

*Rydym eisiau clywed gan bobl sy'n bodloni'r meini prawf canlynol:*

- *Byw yng Cymru*
- *Merch 13 oed neu'n hŷn*
- *Mynediad at ddyfais i chi ei defnyddio wrth gymryd rhan mewn gweithdai.*

Pwrpas yr astudiaeth hon:

*Mae'r astudiaeth hon yn ymwneud â'r hyn sy'n bwysig ei gynnwys ar grynoded o unigolyn ar draws lleoliadau addysg, iechyd a chymdeithasol. Mae hyn yn cynnwys sut bydd yn edrych a'r arweiniad ar sut i'w gwblhau.*

*Nod yr astudiaeth hon yw canolbwyntio'r adnodd hwn ar eich anghenion chi, gyda chi'ch hun a gweithwyr proffesiynol yr un mor bwysig mewn gweithdai.*

Cymryd rhan:

*Does dim rhaid i chi gymryd rhan yn yr astudiaeth hon os yw'n well gennych beidio.*

Yr hyn fydd yn digwydd yn yr astudiaeth:

*Mae'r astudiaeth hon yn cynnwys gweithdai trwy Microsoft Teams, lle gallwch chi gyfrannu at drafodaethau, a all fod trwy siarad neu deipio yn y rhan sgwrsio (chat).*

- *Bydd gweithdy Cam 1 yn cynnwys cyfranogwyr fel chi'ch hun, yn trafod y proffil un dudalen gyfredol, a'r hyn y byddech chi'n ei gynnwys pe gofynnir i chi ei gwblhau amdanoch chi'ch hun. Ni fydd unrhyw weithwyr proffesiynol yn y gweithdy hwn, a fydd, gobeithio, yn gwneud i chi deimlo'n fwy cyfforddus (dim mwy na 90 munud)*
- *Bydd gweithdy Cam 2 yn cynnwys yr holl randdeiliaid, lle byddwn yn trafod pwyntiau allweddol y gweithdy blaenorol. Gall hyn gynnwys grwpiau sy'n rhannu'n grwpiau llai, i'ch galluogi i drafod gyda grŵp llai o bobl. Bydd y cam hwn yn gweithio tuag at symud yr adnodd yn ei flaen, a nodi rhai o safbwyntiau allweddol y grŵp (dim mwy na 120 munud)*
- *Bydd gweithdy Cam 3 yn cynnwys y penderfyniadau terfynol a'r newidiadau i'r adnodd, yn ogystal â chael cytundeb gan bawb eu bod yn hapus â'r hyn sydd wedi'i gynhyrchu (dim mwy na 60 munud)*

Preifatrwydd:

*Bydd yr holl wybodaeth a gesglir amdanoch yn ystod yr ymchwil yn cael ei chadw'n gyfrinachol.*

**Teitl y project:** Y 'proffil un dudalen' i ferched awtistig yn eu harddegau: gwerthuso a datblygu gyda rhanddeiliaid allweddol.  
**Rhif project:** 2020-16813

**Cyswllt:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



*Bydd unrhyw wybodaeth a ddefnyddir yn ddiweddarach i adrodd ar y canlyniadau yn cael ei gwneud yn anhysbys fel na fydd modd eich adnabod. Ni fydd modd eich adnabod mewn unrhyw adroddiadau neu gyhoeddiadau dilynol.*

*Pe baech yn datgelu neu'n ein hysbysu y gallech chi, neu rywun arall fod mewn perygl sylweddol o niwed, efallai y bydd angen i ni siarad â gweithwyr proffesiynol eraill. Os gallwn, byddwn yn trafod ac yn egluro hyn yn gyntaf.*

**Beth fydd yn digwydd i'r canlyniadau?**

*Gellir rhannu'r templed cryno a grëwyd erbyn diwedd y gweithdai â phobl eraill i'w helpu i ddeall sut y gallant ei ddefnyddio i gefnogi pobl awtistig. Ni fyddant yn gwybod pwy a'i gwnaeth, na'ch bod wedi cymryd rhan.*

*Bydd y canfyddiadau'n cael eu cynnwys yn fy nhraethawd PhD, a gellir eu crybwyll mewn cyflwyniadau eraill neu mewn gwaith yn y dyfodol.*

**Gwybodaeth am y gweithdai**

*Bydd gweithdai yn cael eu cynnal gan ddefnyddio Microsoft Teams. Ar ôl ichi gydsynio i gymryd rhan, byddwn yn trefnu amser cyfleus iddo ddigwydd gyda chyfranogwyr eraill. Gallwch ddewis ar y diwrnod i gymryd rhan ai peidio.*

*Anfonir gwybodaeth a manylion atoch mewn digon o amser, gan gynnwys cyswllt i'r gweithdy.*

**Beth yw manteision cymryd rhan?**

*Er nad oes unrhyw gymhellion ariannol i gymryd rhan, y gobaith yw y bydd yr ymchwil hon yn codi ymwybyddiaeth o'ch profiadau, ac yn sicrhau bod eich llais yn cael ei glywed. Y gobaith yw y bydd yr adnodd a ddatblygir yn ddefnyddiol ac y bydd ganddo botensial i'w ddefnyddio.*

*Rydym am sicrhau bod profiadau bywyd go iawn yn dylanwadu ar yr astudiaeth, yn ogystal â sicrhau bod pobl awtistig yn cymryd rhan bob amser fel partneriaid cyfartal â gweithwyr proffesiynol.*

**Beth yw'r risgiau o gymryd rhan?**

*Nid oes unrhyw risgiau ymddangosiadol o gymryd rhan, gan nad yw'r pynciau'n debygol o fod yn sensitif. Fodd bynnag, os ydych chi'n teimlo'n ofidus o gwbl, gallwch gysylltu â'r ymchwilydd neu'r tîm ymchwil.*

*Mae asesiad risg llawn wedi'i gwblhau.*

**Yr hawl i dynnu'n ôl**

*Mae gennych hawl i dynnu eich cydsyniad yn ôl ac unrhyw ddata a gasglwyd ar unrhyw adeg yn ystod yr astudiaeth. Ar ôl i'ch cyfranogiad ddod i ben ac ar ôl i'r data gael ei wneud yn ddienw, ni fydd modd tynnu data'n ôl o'r astudiaeth. Byddwn yn ei gwneud yn glir pan fydd hyn wedi'i wneud.*



**Teitl y project:** Y 'proffil un dudalen' i ferched awtistig yn eu harddegau: gwerthuso a datblygu gyda rhanddeiliaid allweddol.

**Rhif project:** 2020-16813

**Cyswllt:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



*Gallwch ddewis p'un ai i gymryd rhan yn y gweithdai, yn ogystal â faint rydych chi'n ei gyfrannu at drafodaethau.*

#### *Recordio*

*Bydd gweithdai'n cael eu recordio i sicrhau ein bod yn dal popeth a ddywedwyd yn gywir. Caiff yr holl recordiadau sain eu storio ar ddyfais sydd wedi ei hamgryptio a dim ond y tîm ymchwil fydd yn cael eu clywed. Cânt eu dinistrio ar ôl pum mlynedd.*

#### *Cymeradwyo'r astudiaeth*

*Cafodd yr astudiaeth ei chymeradwyo gan Bwyllgor Moeseg Academiaidd y Gwyddorau Gofal Iechyd a Meddygol (2020-16813)*

#### *Cysylltu ynglŷn ag unrhyw bryderon*

*Os oes gennych unrhyw gwynion am yr astudiaeth hon, cysylltwch â:*

- *Dr Jaci Huws (Goruchwyliwr y Project) - [j.huws@bangor.ac.uk](mailto:j.huws@bangor.ac.uk)*
- *Dr Anne-Marie Smith (Goruchwyliwr y Project) - [amsmith@bangor.ac.uk](mailto:amsmith@bangor.ac.uk)*
- *Dr Lynne Williams (Pennaeth yr Ysgol) - [Lynne.williams@bangor.ac.uk](mailto:Lynne.williams@bangor.ac.uk)*

#### *Unrhyw gwestiynau?*

*Mae pob croeso i chi ein holi os oes gennych unrhyw gwestiynau. Ni ddylech lofnodi'r ffurflen gydsynio i gymryd rhan yn yr astudiaeth os nad ydych wedi cael ateb i'ch cwestiynau i gyd neu os oes gennych unrhyw amheuan.*

## Appendix 22

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



### INFORMATION SHEET

Why you have been asked to participate:

*You are invited to take part in this research as you are aged 13 or over with a diagnosis of autism (the term autism is used but encompasses all related diagnostic terms).*

*We are wanting to hear from people who meet these criteria:*

- *Living in Wales*
- *Female aged 13 or over*
- *Access to a device for you to use when participating in workshops.*

What this study is about:

*This study is about what is important to include on a summary of an individual across education, health and social settings. This includes what it will look like and the guidance about how to complete it.*

*This study aims to focus this tool on your needs, with yourselves and professionals being equally important in workshops.*

Taking part:

*You do not have to take part in this study if you would not like to.*

What this study involves:

*This study involves workshops through Microsoft Teams, where you can contribute to discussions, which can be through speaking or typing in the chat function.*

- *Phase 1 workshop will include participants such as yourself, discussing the current one-page profile, and what you would include if asked to complete it about yourself. No professionals will be within this workshop, which will hopefully make you feel more comfortable (maximum 90 minutes)*
- *Phase 2 workshop will include all stakeholders, where we will discuss the key points from the previous workshop. This may include break out groups to enable you to discuss with a smaller group of people. This stage will work towards progressing the tool and identifying some of the key viewpoints of the group (maximum 120 minutes)*
- *Phase 3 workshop will involve the final decisions and amendments to the tool as well as getting an agreement from everyone that they are happy with what has been produced (maximum 60 minutes)*

Privacy:

*All information which is collected about you during the research will be kept confidential.*

*Any information which is later used in reporting of the results will be anonymised and therefore you will not be recognised. Any subsequent references in reports or publication will not identify.*

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.  
**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



*Should you disclose or inform us that you, or someone else might be in significant danger of harm, we may need to speak to other professionals. If we can, we will discuss and explain this first.*

What will happen to the results?

*The summary template created by the end of the workshops may be shared with other people to help them understand how they can use it to support autistic people. They will not know who made it or that you were involved.*

*The findings will be included in my PhD writing, and may be mentioned in other presentations or future work.*

Workshop information

*Workshops will be conducted using Microsoft Teams. Once you have consented to take part, we will arrange with other participants a convenient time for it to happen. You can choose on the day to take part or not.*

*Information and details will be sent to you in plenty of time, including a link to the workshop.*

What are the benefits of taking part?

*Whilst there are no financial incentives to take part, it is hoped that this research will raise awareness of your experiences and ensure that your voice is heard. It is hoped that the tool developed will be useful and have potential to be used.*

*We want to ensure real life experiences influence the study, as well as ensuring autistic people being always involved as equal partners with professionals.*

What are the risks of taking part?

*There are no perceived risks to taking part, as the topics are not likely to be sensitive. However, if you do experience any distress, you can contact the researcher or research team.*

*A full risk assessment has been completed.*

Right to withdraw

*You have the right to withdraw your consent and any collected data at any time during the study. Once participation has been completed and data anonymised, data will be unable to be withdrawn from the study. We will make it clear when this has been done.*

*You can choose whether to take part in the workshops, as well as how much you contribute to discussions.*

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



#### Recording

*Workshops will be recorded to ensure we accurately capture everything that is said. All audio recordings will be stored on an encrypted device accessible only to the research team. They will be destroyed after five years.*

#### Study approval

*This study has been approved by Healthcare and Medical Sciences Academic Ethics Committee (2020-16813)*

#### Contact with any concerns

*If you have any concerns about how this study is conducted, please contact:*

- Dr Jaci Huws (Project Supervisor) – [j.huws@bangor.ac.uk](mailto:j.huws@bangor.ac.uk)
- Dr Anne-Marie Smith (Project Supervisor) – [amsmith@bangor.ac.uk](mailto:amsmith@bangor.ac.uk)
- Dr Lynne Williams (Head of School) – [Lynne.williams@bangor.ac.uk](mailto:Lynne.williams@bangor.ac.uk)

#### Any questions?

*Please ask us if you have any questions. You should not sign the consent form consenting to take part in the study if you still have unanswered questions or any doubts.*

## Appendix 23

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



### Demographic information

To aid our understanding we need to know some more information about your experiences. It will only be available to the research team and will remain confidential.

Professional role title:

Brief role description:

Any other relevant experience or personal links with ASD?

### Contact information

Please give your contact number and email address below so that we can contact you with further participation instructions.

Phone number:

Email address:

**If you have any concerns about how this study is conducted, please contact:**

Dr Jaci Huws (Project Supervisor) – j.huws@bangor.ac.uk  
Dr Anne-Marie Smith (Project Supervisor) – amsmith@bangor.ac.uk  
Dr Lynne Williams (Head of School) – Lynne.williams@bangor.ac.uk

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



**If you agree with the statements below, please initial and tick each and then sign and date in the area provided.**

1. I confirm that I have read and understand the Information Sheet provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

Initials:

2. I understand that my participation is voluntary. I am free to withdraw my participation at any time without giving a reason.

Initials:

3. I understand that I can contact the researcher, research supervisors or the head of school with any concerns.

Initials:

4. I agree to take part in the workshops.

Initials:

5. I agree for my discussions to be audio recorded.

Initials:

**Consent**

Name:

Signature:

Date:

Name of person taking consent:

Signature:

Date:

**If you have any concerns about how this study is conducted, please contact:**

Dr Jaci Huws (Project Supervisor) – j.huws@bangor.ac.uk

Dr Anne-Marie Smith (Project Supervisor) – amsmith@bangor.ac.uk

Dr Lynne Williams (Head of School) – Lynne.williams@bangor.ac.uk



## Appendix 24

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



### Demographic information

To aid our understanding we need to know some more information about your daughter. It will only be available to the research team and will remain confidential.

Age of child:

Diagnosis and age when diagnosed:

Any other diagnoses? (If yes, please provide details):

### Contact information

Please give your contact number and email address below so that we can contact you with further participation instructions.

Phone number:

Email address:

### Declaration

I (name of parent/guardian) \_\_\_\_\_

am the parent/guardian of (name of child) \_\_\_\_\_

Date \_\_\_\_\_

**If you have any concerns about how this study is conducted, please contact:**

Dr Jaci Huws (Project Supervisor) – j.huws@bangor.ac.uk

Dr Anne-Marie Smith (Project Supervisor) – amsmith@bangor.ac.uk

Dr Lynne Williams (Head of School) – Lynne.williams@bangor.ac.uk

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131

**If you agree with the statements below, please initial and tick each and then sign and date in the area provided.**



1. I confirm that I have read and understand the Information Sheet provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

Initials:

2. I confirm that I have discussed with my child their participation in this study.

Initials:

3. I understand that mine and my child's participation is voluntary. I am free to withdraw my child's participation at any time without giving a reason and my child is also free to withdraw at any time without giving a reason (if this occurs, you will be informed).

Initials:

4. I understand that I can contact the researcher, research supervisors or the head of school with any concerns.

Initials:

5. I agree for my child to take part in the online workshops.

Initials:

6. I agree for my child's discussions to be audio recorded.

Initials:

**Consent**

Name of parent/guardian:

On behalf of:

Signature:

Date:

Name of person taking consent:

Signature:

Date:

**If you have any concerns about how this study is conducted, please contact:**

Dr Jaci Huws (Project Supervisor) – j.huws@bangor.ac.uk  
Dr Anne-Marie Smith (Project Supervisor) – amsmith@bangor.ac.uk  
Dr Lynne Williams (Head of School) – Lynne.williams@bangor.ac.uk



## Appendix 25

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



### Demographic information

To aid our understanding we need to know some more information about you. It will only be available to the research team and will remain confidential.

Age:

Diagnosis and age when diagnosed:

Any other diagnoses? (If yes, please provide details):

### Contact information

Please give your contact number and email address below so that we can contact you with further participation instructions.

Phone number:

Email address:

**If you have any concerns about how this study is conducted, please contact:**

Dr Jaci Huws (Project Supervisor) – j.huws@bangor.ac.uk  
Dr Anne-Marie Smith (Project Supervisor) – amsmith@bangor.ac.uk  
Dr Lynne Williams (Head of School) – Lynne.williams@bangor.ac.uk

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



**If you agree with the statements below, please initial and tick each and then sign and date in the area provided.**

1. I confirm that I have read and understand the Information Sheet provided for the above study. Initials:
2. I confirm that I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.  
Initials:
3. I understand that my participation is voluntary. I am free to withdraw at any time without giving a reason.  
Initials:
4. I understand that I can contact the researcher, research supervisors or the head of school with any concerns.  
Initials:
5. I agree to take part the online workshops.  
Initials:
6. I agree for my discussions to be audio recorded.  
Initials:

**Consent**

Name of parent/guardian:

On behalf of:

Signature:

Date:

Name of person taking consent:

Signature:

Date:

**If you have any concerns about how this study is conducted, please contact:**

Dr Jaci Huws (Project Supervisor) – j.huws@bangor.ac.uk  
Dr Anne-Marie Smith (Project Supervisor) – amsmith@bangor.ac.uk  
Dr Lynne Williams (Head of School) – Lynne.williams@bangor.ac.uk

## Appendix 26

**Title of project:** The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

**Project number:** 2020-16813

**Contact:** Bethany Edwards, edu4a3@bangor.ac.uk, 01248 383131



**Parental consent received:** Yes No

**Date received:**

### DECLARATION

**If you agree with the statements below, please initial and tick each and then sign and date in the area provided.**

1. I know what I am going to do in this study, and I understand why I am taking part. I have been able to ask questions and have had them answered.

Initials:

2. I know that I can stop at any time and I do not have to say why.

Initials:

3. I know that I can talk to my parent/guardian and the researcher if I have any questions.

Initials:

4. I agree that what I say can be recorded by the researcher.

Initials:

5. I agree to take part in the online workshops.

Initials:

Name:

Signature:

Date:

Name of person taking consent:

Signature:

Date:

**If you have any concerns about how this study is conducted, please contact:**

Dr Jaci Huws (Project Supervisor) – j.huws@bangor.ac.uk

Dr Anne-Marie Smith (Project Supervisor) – amsmith@bangor.ac.uk

Dr Lynne Williams (Head of School) – Lynne.williams@bangor.ac.uk

## Appendix 27

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

Project number: 2020-10013

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 301131

**PRIFYSGOL  
BANGOR  
UNIVERSITY**

**Croeso / Welcome**

**Friday 26th February**

*This workshop should last  
around 90 minutes.*

Group: 1  
Phase: 1

1

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

Project number: 2020-10013

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 301131

**PRIFYSGOL  
BANGOR  
UNIVERSITY**

**Introduction**

**Who am I?  
Purpose?**

**Session schedule**

*Introductions to participating and group agreement.  
Ice breaker activity.  
Profile activity.  
BREAK-5 minutes  
Discussion about key points.  
Other feedback and comments.  
Conclusion and explanation about phase 2.*

Group: 1  
Phase: 1

2

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

Project number: 2020-10013

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 301131

**PRIFYSGOL  
BANGOR  
UNIVERSITY**

**Group agreement**

If you must leave at any time mid-workshop, let the researcher know. This is to ensure your safety.

Confidentiality / privacy

Respectful of others

If you want to contribute, use the hand's up function.

Any other things you want to be included?

Group: 1  
Phase: 1

3

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.


Project number: 2020-10013

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 301131

**PRIFYSGOL  
BANGOR  
UNIVERSITY**

**Ice breaker**

**Name**  
**Your favourite subject or hobby**



*For example...*  
*I'm Beth my favourite subject is participatory autism research*  
*In my spare time I enjoy playing the flute.*

Group: 1  
Phase: 1

4

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders. Contact: Bethany Edwards, edb46@bangor.ac.uk, 01248 303131 Project number: 2020-16813

**PRIFYSGOL BANGOR UNIVERSITY**

**Case profile activity**

Use your own personal experiences and how you would approach this if you were completing a one-page profile.

*What people appreciate about me (like and admire)*

*What's important to me*

*How to support me*

*Other comments?*

Group: 1 Phase: 1

5

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders. Contact: Bethany Edwards, edb46@bangor.ac.uk, 01248 303131 Project number: 2020-16813

**PRIFYSGOL BANGOR UNIVERSITY**

**Break – 5 minutes**

Group: 1 Phase: 1

6

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders. Contact: Bethany Edwards, edb46@bangor.ac.uk, 01248 303131 Project number: 2020-16813

**PRIFYSGOL BANGOR UNIVERSITY**

**Discussion – activity**

*How did you find completing the one-page profile?*

*What do you think is good about it?*

*Can anything be improved?*

*Focusing on autistic females, is it suitable / fit for purpose?*

*Other comments?*

Group: 1 Phase: 1

7

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders. Contact: Bethany Edwards, edb46@bangor.ac.uk, 01248 303131 Project number: 2020-16813

**PRIFYSGOL BANGOR UNIVERSITY**

**Feedback / comments (open)**

For example...

*Thoughts about the importance of this study:*

*Thoughts about the sample group (autistic teenage girls)*

*Applications in your life?*

Group: 1 Phase: 1

8

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders. Contact: Bethany Edwards, edb46@bangor.ac.uk, 01248 303131 Project number: 2020-16813

**PRIFYSGOL BANGOR UNIVERSITY**

**Next stage**

This will include both groups taking part in a combined workshop. This will include yourselves and the professional stakeholders.

I will get in touch in the next two weeks with suggested dates and times.

This second phase will be focused on developing / adapting the current tool.

Group: 1 Phase: 1

9

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders. Contact: Bethany Edwards, edb46@bangor.ac.uk, 01248 303131 Project number: 2020-16813

**PRIFYSGOL BANGOR UNIVERSITY**

**Questions?**

After the workshop, if you have any thoughts or comments that you didn't share, please send them to me by email so that they can be included.

**Thank you for taking part.**

Group: 1 Phase: 1

10

## Appendix 28

Title of project: The 'voice-up profile' for autistic teenage girls: evaluation and development with key stakeholders. Project number: 2020-16815 Contact: Bethany Edwards, edeb401@bangor.ac.uk, 01248 303131

**PRIFYSGOL BANGOR UNIVERSITY**

**Croeso / Welcome**

**w/c Monday 22nd February**

*This workshop should last around 90 minutes.*

Group: 2 Phase: 1

1

Title of project: The 'voice-up profile' for autistic teenage girls: evaluation and development with key stakeholders. Project number: 2020-16815 Contact: Bethany Edwards, edeb401@bangor.ac.uk, 01248 303131

**PRIFYSGOL BANGOR UNIVERSITY**

**Introduction**

**Who am I?  
Purpose?**

**Session schedule**

*Introductions to participating and group agreement.  
Ice breaker activity:  
Profile activity:  
BREAK-5 minutes  
Discussion about key points.  
Other feedback and comments.  
Conclusion and explanation about phase 2.*

Group: 2 Phase: 1

2

Title of project: The 'voice-up profile' for autistic teenage girls: evaluation and development with key stakeholders. Project number: 2020-16815 Contact: Bethany Edwards, edeb401@bangor.ac.uk, 01248 303131

**PRIFYSGOL BANGOR UNIVERSITY**

**Group agreement**

If you must leave at any time mid-workshop, let the researcher know. This is to ensure your safety.

Confidentiality / privacy

Respectful of others

Any other things you want to be included?

Group: 2 Phase: 1

Title of project: The 'voice-up profile' for autistic teenage girls: evaluation and development with key stakeholders. Project number: 2020-16815 Contact: Bethany Edwards, edeb401@bangor.ac.uk, 01248 303131

**PRIFYSGOL BANGOR UNIVERSITY**

**Case profile activity**

Group: 2 Phase: 1

5

Title of project: The 'voice-up profile' for autistic teenage girls: evaluation and development with key stakeholders. Project number: 2020-16815 Contact: Bethany Edwards, edeb401@bangor.ac.uk, 01248 303131

**PRIFYSGOL BANGOR UNIVERSITY**

**Ice breaker**

Group: 2 Phase: 1

Title of project: The 'voice-up profile' for autistic teenage girls: evaluation and development with key stakeholders. Project number: 2020-16815 Contact: Bethany Edwards, edeb401@bangor.ac.uk, 01248 303131

**PRIFYSGOL BANGOR UNIVERSITY**

Charlotte is a quiet, well-behaved 14-year-old girl in a mainstream school and has a diagnosis of autism.

- Charlotte has some teaching assistant support for dyslexia and is in the middle set for all her subjects.
- She feels as though she is struggling at school and feels isolated.
- She is permanently anxious about the quality of her work.
- She is expected to achieve good results and go to university – she just needs more support to access the social world of her peers to develop the self-confidence to approach the challenges of school life, and to not be missed through her lack of challenging behaviours.
- She likes to sit at the back of class and doesn't put her hand up or answers questions.
- Sitting at the back of class allows her to observe her peers and plan her reactions according to what she sees other people doing, she may not work it out on her own.
- Her reluctance to answer questions comes from her strong perfectionism, as she does not want to attempt something she might get wrong, and even if she does know the answer, she feels too shy to open herself up to attention from her peers.
- She likes to follow rules and interprets instructions literally.
- She can be the last to laugh at a joke, as she waits until she is sure that everyone else is laughing.
- She may be quiet, but she is not automatically 'ok'.
- Charlotte's best friend is called Jessica.
- Charlotte has really enjoyed drama and acting since moving to high school. She appeared good at it so was offered a place at a prestigious youth theatre. This interest has now expanded to include the literature in the drama – she was involved with, so much so, she can recite large sections of her favourite Shakespeare.

Group: 2 Phase: 1

6

Title of project: The 'voice-up profile' for autistic teenage girls: evaluation and development with key stakeholders. Project number: 2020-16815 Contact: Bethany Edwards, edeb401@bangor.ac.uk, 01248 303131

**PRIFYSGOL BANGOR UNIVERSITY**

**Case profile activity**

Which information from it do you view as important?

*What people appreciate about me (like and admire)*

*What's important to me*

*How to support me*

*Other comments?*

Group: 2 Phase: 1

7

Title of project: The 'voice-up profile' for autistic teenage girls: evaluation and development with key stakeholders. Project number: 2020-16815 Contact: Bethany Edwards, edeb401@bangor.ac.uk, 01248 303131

**PRIFYSGOL BANGOR UNIVERSITY**

**Break – 5 minutes**

Group: 2 Phase: 1

8

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

Project number: 2020-10613

Contact: Anthony Edwards, a.edwards@bangor.ac.uk, 01248 363131

**PRIFYSGOL  
BANGOR  
UNIVERSITY**

**Discussion – activity**

*How did you find completing the one-page profile?*

*What do you think is good about it?*

*Can anything be improved?*

*Focusing on autistic females, is it suitable / fit for purpose?*

*Other comments?*

Group: 2  
Phase: 1

9

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

Project number: 2020-10613

Contact: Anthony Edwards, a.edwards@bangor.ac.uk, 01248 363131

**PRIFYSGOL  
BANGOR  
UNIVERSITY**

**Feedback / comments (open)**

For example...

*Thoughts about the importance of this study.*

*Thoughts about the sample group (autistic teenage girls)*

*Applications in your life?*

Group: 2  
Phase: 1

10

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

Project number: 2020-10613

Contact: Anthony Edwards, a.edwards@bangor.ac.uk, 01248 363131

**PRIFYSGOL  
BANGOR  
UNIVERSITY**

**Next stage**

This will include both groups taking part in a combined workshop. This will include yourselves and autistic people who are taking part.

I will get in touch in the next two weeks with suggested dates and times.

This second phase will be focused on developing / adapting the current tool.

Group: 2  
Phase: 1

11

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders.

Project number: 2020-10613

Contact: Anthony Edwards, a.edwards@bangor.ac.uk, 01248 363131

**PRIFYSGOL  
BANGOR  
UNIVERSITY**

**Questions?**

After the workshop, if you have any thoughts or comments that you didn't share, please send them to me by email so that they can be included.

**Thank you for taking part.**

Group: 2  
Phase: 1

12

## Appendix 29

Title of project: The 'one-page profile' for autistic language profile evaluation and development with key stakeholders.

Project number: 2020-16815

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 383131

**PRIFYSGOL BANGOR UNIVERSITY**

**Croeso / Welcome**

**Insert date here**

***This workshop should last around 2 hours.***

Groups: 1 & 2  
Phase: 2

1

Title of project: The 'one-page profile' for autistic language profile evaluation and development with key stakeholders.

Project number: 2020-16815

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 383131

**PRIFYSGOL BANGOR UNIVERSITY**

**Introduction**

**Session schedule**

*Introductions to workshop and group agreement.  
Ice breaker activity.  
Feedback from first phase and discussion.  
Topic areas / subtitles to be prompts on the created tool.  
BREAK- 10 minutes  
Guidance to accompany document discussion.  
Conclusion and explanation about phase 3.*

Groups: 1 & 2  
Phase: 2

2

Title of project: The 'one-page profile' for autistic language profile evaluation and development with key stakeholders.

Project number: 2020-16815

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 383131

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**Group agreement**

If you must leave at any time mid-workshop, let the researcher know. This is to ensure your safety.

Confidentiality / privacy – what people say stays within the workshop.

Respectful of others – people may have had bad experiences in the past with specific services or processes. These aren't personal.

If you want to contribute, use the hand's up function or type in the chat.

Groups: 1 & 2  
Phase: 2

3

Title of project: The 'one-page profile' for autistic language profile evaluation and development with key stakeholders.

Project number: 2020-16815

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 383131

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**Ice breaker**

Name

Your group in phase 1 ('professional' / 'autistic')

A meal that you enjoy

*For example...*

*Hello, Beth ydy I.  
Dyma fy mchwil PhD ac rwy'n awtistig.  
Dw I'n hoffi bwyta pysgod, sgloidion a phys.*

*Hello, I'm Beth.  
This is my PhD research and I'm autistic.  
I like eating fish, chips and peas.*

Groups: 1 & 2  
Phase: 2

4



Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders. Project number: 2020-10015  
Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 303131

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### Summary of discussions

- Hard to convey level of detail that is needed. Boxes serve teachers purposes, easy to do, does not serve the purpose of getting the full picture (complexities of females, e.g., masking). Training around flexible profiles, move away from 'one-size fits all'. Wider familiarization of the documents and training guidance provided alongside the tool.
- Linking in with wider documents, including IDP Links for further information.
- Culture around it, tick box exercise
- Importance of person themselves involved. 'ownership' Linked with reviews, should be used more in day to day.
- Identity (specifically important in adolescence). Community choice of language – identity first.
- Overriding themes of communication and sensory. Need sensory considerations added (specific to that person).
- Facilitating the creation of the profile (level of understanding and co-operation from professionals) to make sure that we are selecting right and most important bits.
- 'If you don't understand please ask for clarity.'
- Preferred method of communication. Reinforce ability to communicate but it can be variable. Importance of preferred communication style – may be dependent of the context.
- Options of more pictures and images (e.g., sensory).
- Importance of consistency across settings (e.g., primary better than secondary?).

Group: 1 & 2  
Phase: 2

5

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders. Project number: 2020-10015  
Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 303131

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### Summary of discussions

- Not automatically 'ok'. We pick up loud behaviour, quiet can go under the radar.
- Importance of relevance to enable quick understand without going through the whole file.
- Communication preferences, e.g., written instructions are preferable. Clear direct instructions. Clarity of demand when discussing something or in a certain context.
- "If you don't do this... this will happen" in the context of triggers. Sensory: hyper/hypo sensitive. Important to know – link with distress. How someone reacts when they are not coping, things to look out for. 'triggers'.
- Making the environment comfortable. They should not have to change, we can very easily change the environment to work for them. Out of the classroom, breaktimes, trips, lunchtime?
- Variability in how autistic people present in different situations.
- Example given of writing one for yourself, and then removing personalisation to see if other people can know who it is. 'Should be able to pick up, without name or picture, and know exactly who that person is'.
- Focus on what the individual wants to include, what is important to them. In secondary, who knows the person best – personal tutor/ALNCo? Collaboration.
- Everyone to understand the importance of them, working document, dated.
- Experiences of changes/ transitions.

Group: 1 & 2  
Phase: 2

6

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders. Project number: 2020-10015  
Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 303131

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### Summary of discussions

- Diagnosis and photo personal preference. Importance of choice. 'like and admire' abstract concept.
- Specific strategies rather than generalised. 'signs I may be starting to struggle'. Camouflaging/ masking.
- Quick and easy to read. New staff to have read it before meeting – some recognition it has been done, for example signature. Wider training and awareness of autism – everyone is different.
- Sensory considerations. Strategies being clear, feel more able to use them with reduction of perception of being told off (shouting/ confrontation). Sensing information and reinforce not 'misbehaving'. Personal space.
- Option to complete independently at home, with support (either parent/ trusted person or teacher). Importance of the individual having the choice and time to process the options and make an informed decision.
- Safe space/ quiet room identified – safety of knowing where they are – link back to worries of being told off.
- Document acting as agreement that they can use them – permission – viewing document as 'official'. Perception of being viewed as overreacting in the past.
- Hierarchy – feeling unable to ask questions – all views equal (autistic people know themselves the best).
- Variation in levels of communication, e.g., when extremely anxious unable to speak.
- Ability to phone and speak to 'safe person' (ideas of not being aloud phone in school).
- Document being fluid. Encourage to ask questions rather than assume.

Group: 1 & 2  
Phase: 2

7

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders. Project number: 2020-10015  
Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 303131

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### Summary of discussions

- Fear of conflict/ going against someone else (hierarchy). Importance of being believed, viewed as equal rather than dismissed. Some people may include statements that challenge previous misconceptions, 'I'm not always ok', or 'I'm autistic not overreacting'. Role of implementation, awareness of the document and valued, idea of 'proof'.
- Awareness of co-occurring diagnoses embedded within profile, may also require a section for themselves. One page may not be enough space. Importance of navigation (links to other documents, subtitles, visual presentation).
- Takes time to build up a rapport and trust. May not always be able to identify what one needs, but with prompts may help. Someone close may be able to contribute. Though, caution that it doesn't become their perceptions.
- Flexibility within headings. Better to be blunt and to the point. Safe space and area to escape. Importance of environment/ linking with sensory. Lots of perceived small things can lead to a meltdown.
- Range of levels of communication/ attention functioning. 'subtle things' rather than obvious behaviours that can be seen such as behavioural 'outbursts'. Capacity/ functioning/ communication levels can vary. Decision or capacity in one instant does not mean that's applicable across other instances.
- No idea how would respond to values things others admire. Focusing upon other people again rather than them.
- Acknowledge individual experiences, drawing away from perceptions of 'severity' and 'functioning'.
- Masking everyone assumes I'm ok but I may not be. Trying to fit in, not be a nuisance or cause trouble.

Group: 1 & 2  
Phase: 2

8

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders. Project number: 2020-10015  
Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 303131

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### Summary of discussions

Professional group	Autistic group
<ul style="list-style-type: none"> <li>• Tool itself varied in how it was used (geographical location).</li> <li>• Reinforced the need for the tool to be up to date and contain appropriate information.</li> <li>• Discussions of wider issues such as focus upon referring for diagnosis or seeking external support.</li> <li>• Tool was useful but needed to be clear who it is written for, rather than providing generic statements.</li> <li>• Importance of including identity preferences (e.g., autistic or Asperger's), communication preferences and specific sensory experiences.</li> <li>• Specialist provisions deemed to use them more successfully.</li> <li>• Perception of it being increasingly important during adolescence due to transitions and the range of staff.</li> </ul>	<ul style="list-style-type: none"> <li>• Topic areas viewed as vague, not as useful if it was to be used in everyday world.</li> <li>• Highlighted the possible benefit of having a tool that could be tailored to an individual's needs including the sub-titles/ information included.</li> <li>• Importance of flexibility.</li> <li>• May need to be longer than one page.</li> <li>• Importance of producing as a proactive document rather than reactive.</li> <li>• Perception of standing out or being told off.</li> <li>• Ensuring the autistic person has the choice.</li> </ul>

Group: 1 & 2  
Phase: 2

9

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders. Project number: 2020-10015  
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### Key themes from phase 1

1. The tool needs to have specific information that is personalised including warning signs of struggling, triggers, and sensory considerations. For females, because of masking difficulties, having this would help people understand them. Another thing was to have a safe space identified on there as well as a person that they trusted and could be a calming positive influence in a meltdown situation. Idea of being proactive rather than reactive.
2. The titles/ sections on the profile should reflect the individual, suggestions of selecting titles that are suitable rather than having a single standardised 'form' was popular – discussions included how passports had been used variably but typically these focused upon behaviour and a medical model (rather than a social model).
3. The tool needs to be used, reviewed, and updated as an ongoing process, rather than being aligned with ALNIDP reviews. Overall feeling that this would have a more positive influence if it is used day to day, then using the current version for the purpose of reviews. In addition, it was said to be important that guidance information is clear, but to have someone who reviews them to ensure they are being completed. Wider training awareness about autism, specifically females who may mask difficulties.

Group: 1 & 2  
Phase: 2

10

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### Discussion of summaries and key themes

Group: 1 & 2  
Phase: 2

11

Title of project: The 'one-page profile' for autistic teenage girls: evaluation and development with key stakeholders. Project number: 2020-10015  
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### Topics and themes which may be included on the tool

*These would be optional and prompts for people to use, rather than being a fixed format.*

- Description of topic or theme.
- Example of the information to be included.
- Any explanation to accompany theme.

Group: 1 & 2  
Phase: 2

12

Title of project: The 'one-page profile' for autistic language profile evaluation and development with key stakeholders.

Project number: 2020-16815

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 303131

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**BREAK – 10 minutes**

Groups: 1 & 2

Phase: 2

13

Title of project: The 'one-page profile' for autistic language profile evaluation and development with key stakeholders.

Project number: 2020-16815

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 303131

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**Construction of a tool, including how it will look.**

Groups: 1 & 2

Phase: 2

14

Title of project: The 'one-page profile' for autistic language profile evaluation and development with key stakeholders.

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**Discussion about guidance document, what needs to be included?**

Groups: 1 & 2

Phase: 2

15

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Project number: 2020-16815

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**Conclusion and explanation about phase 3.**

After this phase, I shall summarise what has been discussed in the form of a draft document of the tool we have created.

You will all be sent this and asked for any feedback in advance of the final session (aiming to send 6<sup>th</sup> April).

Phase 3 will be a shorter 60-minute session to go through the document, make any final changes that have arisen from feedback and agree the final document.

**Monday 12<sup>th</sup> April (1:30pm OR 3pm).**

Groups: 1 & 2

Phase: 2

16

Title of project: The 'one-page profile' for autistic language profile evaluation and development with key stakeholders.

Project number: 2020-16815

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 303131

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**Questions?**

After the workshop, if you have any thoughts or comments that you didn't share, please send them to me by email so that they can be included.

**Thank you for taking part.**

Groups: 1 & 2

Phase: 2

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## Appendix 30

Title of project: The 'voice-use profile' for autistic language price evaluation and development with key stakeholders.

Project number: 2020-16813

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 363131

**PRIFYSGOL BANGOR UNIVERSITY**

**Croeso / Welcome**

**Monday 12<sup>th</sup> April**

*This workshop should last around 1 hour.*

Group: 1 & 2

Phase: 1

1

Title of project: The 'voice-use profile' for autistic language price evaluation and development with key stakeholders.

Project number: 2020-16813

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 363131

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**Session schedule**

*Introductions.*

*Feedback and comments on the contexts section.*

*Feedback on guidance.*

*Feedback on the topic areas / table.*

*Feedback on example templates.*

*Any other comments?*

*Conclusion.*

Group: 1 & 2

Phase: 1

2

Title of project: The 'voice-use profile' for autistic language price evaluation and development with key stakeholders.

Project number: 2020-16813

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 363131

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**Introduction**

We will be going through the draft report in sections.

If there is anything you don't feel able to say in the workshops there is opportunity to send feedback via email.

Group: 1 & 2

Phase: 1

3

Title of project: The 'voice-use profile' for autistic language price evaluation and development with key stakeholders.

Project number: 2020-16813

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 363131

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**Key concepts – social and cultural**

*UN conventions.*

*Inclusion, equality and diversity*

*Awareness*

*Participation and collaboration*

**Key concepts – contextual**

*Spectrum*

*Presentation*

*Camouflaging / masking*

*Stimming*

*Anxiety*

*"Translator"*

Group: 1 & 2

Phase: 1

4

Title of project: The 'voice-use profile' for autistic language price evaluation and development with key stakeholders.

Project number: 2020-16813

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 363131

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**Guidance section**

*Reflexivity*

*Presentation*

*Implementation*

*Innovation*

*Embedding*

*Training*

Group: 1 & 2

Phase: 1

5

Title of project: The 'voice-use profile' for autistic language price evaluation and development with key stakeholders.

Project number: 2020-16813

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 363131

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**Topic areas (including table)**

*Overview*

*Communication*

*Anxiety / stressors*

*Environment*

*Community*

*Care needs*

*Sensory*

*Meltdown / shutdown*

*Masking*

*Other*

*Permissions*

*Review*

Group: 1 & 2

Phase: 1

6

Title of project: The 'voice-use profile' for autistic language price evaluation and development with key stakeholders.

Project number: 2020-16813

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 363131

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**Example templates**

*Version 1*

*Version 2*

*Version 3*

Group: 1 & 2

Phase: 1

7

Title of project: The 'voice-use profile' for autistic language price evaluation and development with key stakeholders.

Project number: 2020-16813

Contact: Bethany Edwards, edwardsb@bangor.ac.uk, 01248 363131

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**Any other comments?**

Group: 1 & 2

Phase: 1

8

### Conclusion

*All the comments and feedback received will be incorporated into the report.*

*The final report will then be sent to you along with debriefing information.*

*Thank you so much for taking part.*

## Appendix 31

### Hydref 2021

*I'r sawl y bo'n berthnasol,*

*Rydych wedi eich nodi fel rhywun a all weld canfyddiadau fy PhD yn ddefnyddiol yn eich ymarfer dyddiol.*

*Rwyf yng nghramau olaf ysgrifennu fy PhD a hoffwn rannu allbwn fy astudiaeth â rhanddeiliaid eraill yng Nghymru.*

*Gan ddefnyddio gweithdai ar-lein, rwyf wedi cydgynhyrchu adroddiad a oedd yn gosod swyddogaeth proffil un dudalen a phynciau o bwys i ferched awtistig yn eu harddegau. Mae'r adroddiad hwn yn benodol yn cyflwyno fersiwn wedi'i haddasu o'r proffil gyda nifer o wahanol adrannau ac awgrymiadau i'w defnyddio.*

*Mae crynodeb o'r adroddiad ynghlwm wrth y llythyr hwn.*

*Ochr yn ochr â hyn, rwy'n gweithio gyda rhanddeiliaid yn y diwydiant i'w ddatblygu i fod yn offeryn digidol y gellir ei ddefnyddio i gynnal yr offeryn hwn.*

*Os yw hyn yn swnio fel rhywbeth y byddai gennych ddiddordeb yn ei ddefnyddio, cysylltwch â ni.*

*Byddai mynediad at y wybodaeth yn yr adroddiad hwn a'r defnydd posibl ohoni **am ddim**.*

*Hefyd, os hoffech gael y wybodaeth ddiweddaraf am hynt y project, nodwch hyn yn eich e-bost.*


*Os oes gennych unrhyw gwestiynau, mae croeso i chi gysylltu â mi.*

*Yn gywir*



**Bethany A Edwards**  
Myfyrwr PhD  
Ysgol Gwyddorau Meddygol ac Iechyd

E-bost: [edu4a3@bangor.ac.uk](mailto:edu4a3@bangor.ac.uk)  
Ffôn: 01248 383131

 *Rydw i'n siarad rhywfaint o Gymraeg*



### October 2021

*To whom it may concern,*

*You have been identified as someone who may find my PhD findings useful in your daily practice.*

*I am in the final stages of writing up my PhD and am wanting to share the output of my study with other stakeholders within Wales.*

*Using online workshops, I coproduced a report that situated the role of a one-page profile and topics of importance for autistic teenage girls. Specifically, this report presents an adapted version of the profile with a range of sections and prompts to be used.*

*A snapshot of the report is attached to this letter.*

*Alongside this, I am working with industry stakeholders to develop this into a digital tool that can be used to host this tool.*


*If this sounds like something you would be interested in accessing, please get in touch.*

*The access and potential use of the information within this report would be **free**.*

*Additionally, if you would like to be kept updated with the project's progress, please state this in your email.*


*If you have any questions, please get in touch.*

*Kind regards*



**Bethany A Edwards**  
PhD Student  
School of Medical and Health Sciences

Email: [edu4a3@bangor.ac.uk](mailto:edu4a3@bangor.ac.uk)  
Phone: 01248 383131

 *I can speak some Welsh*



## Appendix 32

### Bethany Edwards

---

**From:** Bethany Edwards  
**Sent:** 06 May 2021 10:42  
**Subject:** Autistic females research - debriefing  
**Attachments:** Final report profile autistic teenage girls MAY 2021.pdf

*Dear participant,*

*We have now come to the end of the participation for this study. We have co-created a document that focuses upon embedding the one-page profile in practice for autistic teenage girls. Within this, we have used our experiences to include examples of topics that may be relevant, as well described wider concepts, such as participation. Your contributions within the workshops have been very useful.*

*I have attached the final document for you. I hope that this document will add to knowledge of the needs of autistic females and encourage different professionals to work together to best support you. This summary template may be shared with other people to help them understand how they can use it to support autistic people. They will not know who made it or that you were involved. As we have completed the workshops, your data has been edited to remove things which could identify you.*

*Thank you for your participation. If you have any further questions, please get in touch.*

**Bethany A. Edwards**

*Myfyrwr PhD / PhD student  
Ysgol Gwyddorau Iechyd / School of Health Science*

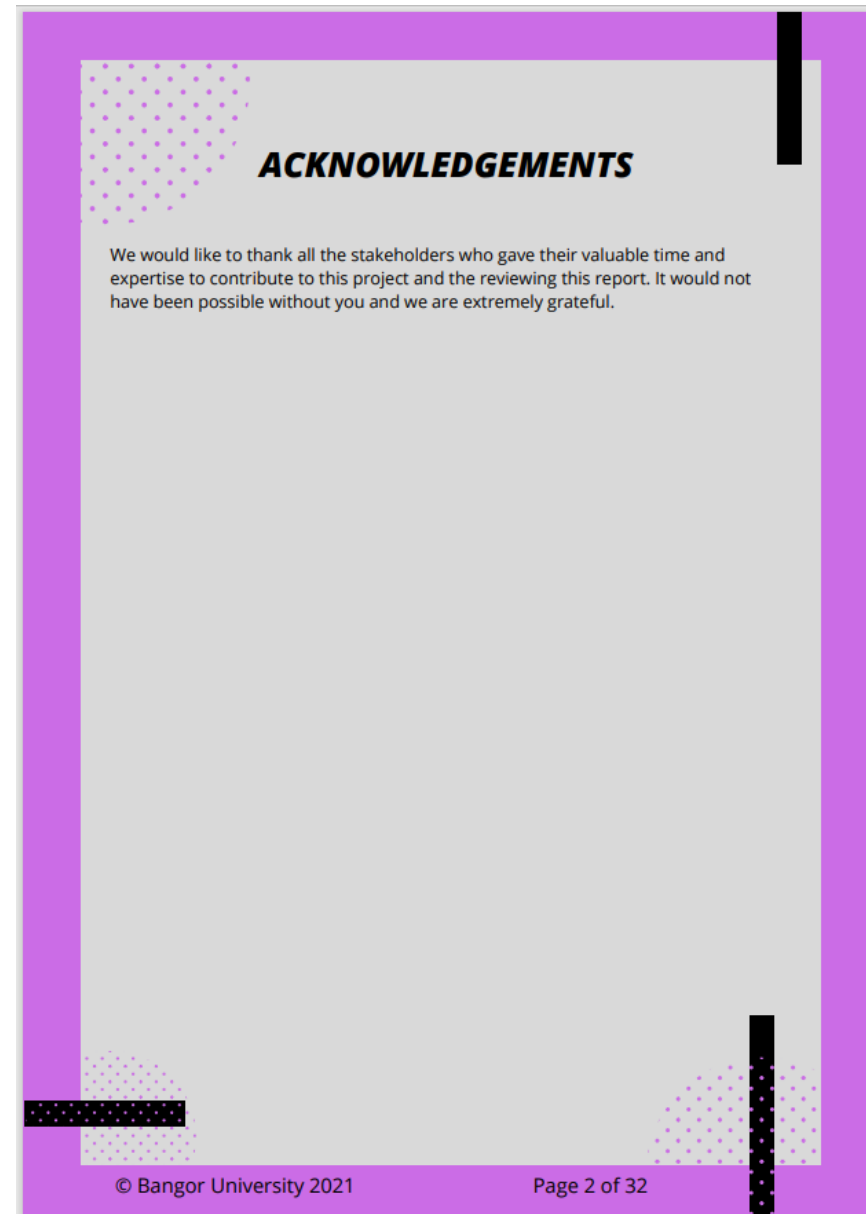
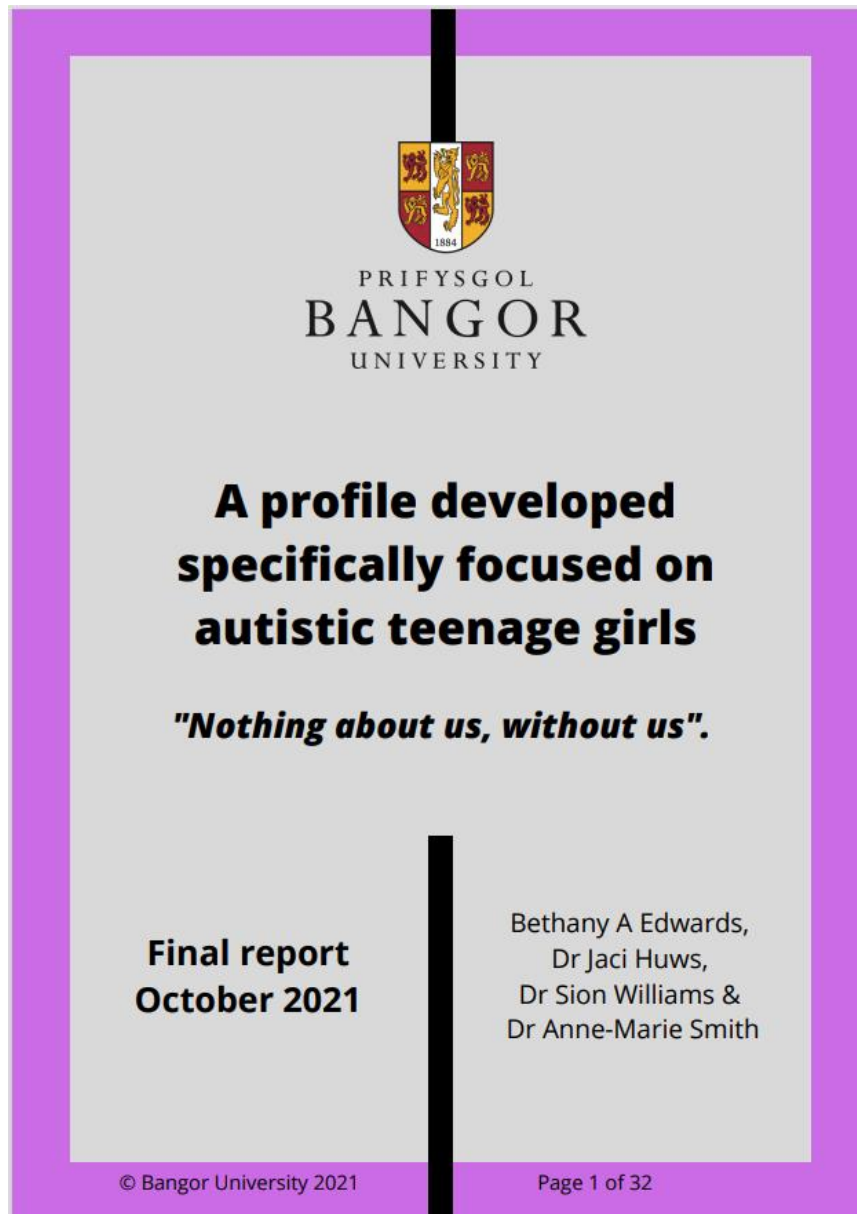
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*Ffôn / Tel: 01248 38(3131)  
E-bost / Email: edu4a3@bangor.ac.uk  
Twitter: @BethAnneBangor*

*\*Byddaf weithiau'n anfon e-bost y tu allan i oriau arferold gwaith (Dydd Llun i ddydd Gwener, 9am-5pm).  
Plis ymatebwch ar adeg sydd yn dderbynion iti.*

*\*I sometimes send emails outside of usual working hours (Monday to Friday, 9am-5pm). Please reply at a time that's convenient for you.*





## PREFACE

### Background

This project was facilitated by a PhD candidate at Bangor University (the author) in collaboration with a range of stakeholders from across Wales.

The one-page profile is a document that forms part of the review process for Children and Young People in Wales with Additional Learning Needs. The information about the tool and the guidance was taken from 'Person Centred Practice in Education – a guide for early years, schools and colleges in Wales' (2015):

“The foundation of person-centred support, a one-page profile contains key information about an individual's character, gifts and talents; what is important to them; and the best way to support them”.

### Method

This project commenced by evaluating the current tool, specifically focusing on autistic teenage girls. Through these discussions, it became clear that the one-page profile was being used regularly, though it would need to be adapted to be more suitable for everyday use.

The process consisted of three phases, all conducted through online participatory workshops:

1. Initial discussions about the tool and discussing the information which may be included. General discussions surrounding stakeholders' experiences of one-page profiles and specific thoughts pertaining to autistic teenage girls.
2. Key themes/prompts to be included in the new 'tool' were discussed as well as the guidance which would be needed to accompany it.
3. Agreement of the final tool among the group.

There were two stakeholder groups that participated, namely professionals involved with autistic females, and autistic females. The professional group included a range of sectors, including education, health care, social care, advocacy, and academia. In total, 19 individuals were involved.

<https://gov.wales/sites/default/files/publications/2019-01/person-centred-practice-in-education-a-guide-for-early-years-schools-and-colleges-in-wales.pdf>

## PREFACE

### Findings

Through the collaborative process, it was understood that the tool as it stands is not appropriate for daily use. Further, a large degree of variation in how they were completed across different geographical locations and sectors was described. For example, it was perceived that mainstream educational settings were not utilising them appropriately, with some descriptions referring to the view of them being:

“a box ticking exercise” (Stakeholder quote).

It was decided that the guidance within this project should provide practical prompts and questions to aid the development of the profile, as well as reinforcing the need for autistic people to be involved in the process. These questions are not exhaustive and utilising other tools as described in the Welsh Government's document is recommended.

We have included some specific areas that were identified through this project, accompanying them with some context and applicable questions or prompts. The report is concluded by providing a few templates which are considered suitable for a good one-page profile.

The creation of an individual's one-page profile should be done to best reflect their needs, though we recognise it to be useful for professionals to have a recognisable structure and layout to the document to make it easy to access. The stakeholder group also felt it important to include information about the implementation and review of the tool. Specifically, in ensuring that it used in the most effective way.

### More information

For more information about the content of this document, please contact Bethany Edwards.

Email: [edu4a3@bangor.ac.uk](mailto:edu4a3@bangor.ac.uk)



## BACKGROUND

### One page profile purpose

The purpose of this version of the profile is to ensure that autistic teenage girls (along with other individuals with additional learning needs) can be best supported across education, health, and social care. Through the stakeholders' vast experiences of this population, specific themes and topic areas were identified that may be pertinent and needing to be included. It was specifically noted that the information that needs to go on these documents may not be easily identified.

Therefore, we reinforce the need for this to be a collaborative process with an open dialogue between the autistic person, their family, and the professionals within a setting.

### Additional Learning Needs (ALN) transformation programme

The Additional Learning Needs and Education Tribunal (Wales) Act was passed by the National Assembly in December 2017 and gained Royal Assent in January 2018. This encompasses regulations and an ALN code.

### What is changing?

The system will transform separate systems for special educational needs (SEN) and learning difficulties and/or disabilities (LDD) into one system that supports learners from 0 to 25 with ALN.



For more information about this follow this link:  
<https://gov.wales/additional-learning-needs-transformation-programme>.

## BACKGROUND

### Key concepts – social and cultural

As part of the implementation of this version of the profile, it was considered important that a background of some concepts was provided. These are not specific to autistic females; however, they stem from the cultural shift identified as being needed to maintain the best practices.

### United Nations Convention on the Rights of Persons with Disabilities (CRPD)

This convention is underlined by several general principles, including:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.
2. Non-discrimination.
3. Full and effective participation and inclusion in society.
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.
5. Equality of opportunity.
6. Accessibility.
7. Equality between men and women.
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Furthermore, linked to this report, article 24, focusing upon education identify some points to note:

- 2c) Reasonable accommodation of the individual's requirements is provided.
- 2d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education.
- 2e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>

## BACKGROUND

### Inclusion, equality and diversity

Various definitions of these terms exist. Through group discussions this understanding was agreed.

Inclusion is a human right for everyone. It includes equal access and opportunities for all, though the way in which these are achieved or accessed may not be the same for everyone. When considering inclusion, it is important to recognise the barriers people face to adapt and navigate them to ensure this human right is met.

It is also important to note that inclusion spans across all events and processes, for example, making the review processes accessible for individuals, their families, and professionals. Equity further enhances this definition as an approach that ensures access to the same opportunities, as well as acknowledging advantage and barriers being in existence.

Diversity put simply is the presence of difference in a setting or environment, existing as a collective rather than an individual.

### Awareness

Whilst the group identified the importance of training surrounding different additional needs and support strategies, it was outlined how this needed to be in addition to a wider cultural awareness of difference and the diversity that is within the community. Awareness also positions individuals as experts in their own lives, and as such, advocated for involvement in the training or guidance given to professionals and stakeholders.

Embedding awareness within stakeholder communities should be situated as an ongoing process, needing review and reflection over time. Professionals should take an active role in increasing their awareness and knowledge.

### Participation and Collaboration

To complete a one-page profile so that it has the most impact, participation and collaboration between stakeholders is crucial. This also needs to ensure that all stakeholders are viewed as equals.

## BACKGROUND

### Participation and collaboration continued

In the table below, this is described in terms of stages that this involves:

<b>Inform</b>	Provide individuals with the information they need, in a format which is accessible. This information should be balanced and objective to allow a decision to be made. This stage should be accompanied by ongoing updates as appropriate with any changes or developments. <i>The way stakeholders are informed needs to allow for time for a decision to be made to ensure that it is fully informed.</i>
<b>Consult</b>	Engage with feedback provided from various stakeholders through accessible methods that view all as equally valid. This should be an ongoing process that is not at a single timepoint. <i>The consequences and implications of consultations should be clear and available to be viewed. In any developments, the role of consultations should be identified.</i>
<b>Involve</b>	To work directly with stakeholders throughout processes to encourage engagement. This should also include involvement with new stakeholders. This involvement also focuses upon understanding the range of views as well as considering these. The way involvement occurs need to be reflexive to the needs of the stakeholders and be at all stages of the decision-making processes. <i>Interpretations of the views expressed should be re-presented to stakeholders for agreement.</i>
<b>Collaborate</b>	To partner with all stakeholders in all aspects of decision making. This should also take account of the preferences individuals have, and where possible, these should be prioritised.
<b>Empower</b>	This involves empowering individuals to get involved with these processes, being able to freely express views without fear of dismissal. Embedding this without society will benefit the other processes discussed. <i>We suggest to fully empower autistic people their role as an expert in their own lives should be promoted.</i>

## BACKGROUND

### Key concepts – contextual

In addition to the wider concepts described, the stakeholders reflected upon terminology and concepts specific to this group of individuals that are not always understood. Whilst there is much literature surrounding these, stakeholders expressed the preference of describing them rather than drawing upon others' accounts.

### Spectrum

The term can be identified with the diagnostic process (Autism Spectrum Condition), though it is important to recognise the meaning of the term in everyday life. Everyone is unique, with areas of strengths and areas to improve. What they are and how they present are what makes an individual unique, with this often being placed upon a spectrum. Autistic people fit on this spectrum.

Further to this, autistic people present in different ways which falls on a more specific spectrum. Historically, terms such surrounding 'functioning' are used at either end of this spectrum, however the group strongly dislike this language. Considerations of communication, social ability and sensory preferences fall within this spectrum. A position on the spectrum is not static, as wider factors, such as anxiety, can influence an individual's experiences. For example, an individual may be able to answer the phone one day, although after a long day at work and a change in routine, may be unable to do this on another day. The profile should aim to present this variability, with individualised 'triggers' and 'signs' professionals can be aware of.

### Presentation

Following on from considerations of 'spectrum', presentation describes how an individual is viewed by the world and those around them. Again, this often draws on ideas of functioning.

This can vary and often is only discussed about 'obvious' or 'behavioural' topics. We suggest that whilst this is important, it is equally valuable to be able to understand the more subtle nuances so that this profile serves to identify. Presentation can also vary depending upon the environment and the level of anxiety an individual is experiencing.

## BACKGROUND

### Presentation continued

We feel the importance with this topic is that the profile contains reference to presentation when it has a purpose, such as:

- What a 'good/usual day' looks like.
- Signs someone may be starting to struggle.
- What a meltdown/shutdown looks like.

### Masking / camouflaging

Masking or camouflaging can be conceptualised under two main areas; hiding challenges or discomfort and adopting a new persona or 'act' to try and fit in with perceived 'social norms'.

1. This can include suppressing needs to fidget, making intentional facial expressions or gestures, or utilising learnt strategies to try and hide these from being detected.
2. Following witnessing successful social interactions, or behaviours that attract popularity, individuals may copy these and re-enact them with the hope they will replicate the outcomes. This can result in feelings of not knowing one's own identity or whether they are liked for the 'persona' or themselves.

This is not specifically restricted to autistic females, though it has been identified to be more prevalent and intense in this group. The stakeholder's experiences, specifically the autistic group resonated with this and identified the complexities that are difficult to be explained.

“as much as someone can understand autism well, unless they're autistic they can't ever fully understand” (participant quote).

### Stimming

A subset of repetitive behaviours, typically referred to as stimming (self-stimulatory behaviours), are part of development for all individuals, though these may be more intense for autistic people.

## BACKGROUND

### Stimming continued

The purpose of these includes:

- They feel good,
- They calm anxiety,
- Awareness of own bodies,
- Help focus / concentration,
- Deal with overwhelm (senses/emotions).

The same behaviour may serve a different purpose for everyone, as well as differing at different times, depending on the wider environment.

Suppressing these is extremely challenging and due to their purpose, can result in other negative emotional or physical experiences. There can also be negative consequences for autistic people, such as perceptions of being odd among peers and punishment due to perceptions that they indicate a lack of engagement.

### Anxiety

Anxiety is common amongst autistic people, who all have their own triggers and coping mechanisms.

Through discussions, some common topics include:

- uncertainty and change,
- sensory triggers,
- social situations,
- expectations and pressures.

Anxiety can also be a contributing factor to being overloaded and experiencing a meltdown. The intensity of anxiety can be dependent upon the topic, as well as cumulative triggers build up over a period. Understanding the effect of anxiety is important to build up a relationship, which is why it features early in the profile.

## BACKGROUND

### "Translator"

During the workshops, this term arose when describing individual's ability to contribute to discussions and decision-making processes. It was conceptualised by being someone who can make the information accessible to the individual, as well as seeking the clarity that will be needed to make a decision.

When in an anxiety provoking situation, such as a review, using a translator was described as a reassurance and took off the pressure of remembering everything discussed. It is important to note that positive experiences of translators were where there was a mutual understanding of the role, a good relationship and rapport, as well as sufficient time for the process to be completed without prior decisions being made.

The role of an advocate was discussed, but stakeholders felt that perceptions of this were that an individual was unaware of what was best. Comparatively, translator is considered more positive, framing it as a filtering process.

“It was discussed how a translator was often the “safe/trusted person” (participant quote).”



## **GUIDANCE**

### **Reflexivity**

Whilst it is a one-page profile, there may be times when that is not enough space. We would encourage the use of more than one page, rather than reducing the information or changing the presentation.

This is only guidance, and we encourage individuals and professionals to use judgement and their own experience to make the decisions about what is and is not included on the document.

### **Presentation**

To ensure that this document remains accessible and beneficial, we have put together some tips when creating the document. In addition, we have provided suggested layouts that could be a starting point when making a profile.

1. Use clear language that is easy to understand.
2. Utilise boxes and other visual features to break up text.
3. Use bullet points to summarise information.
4. Consider the use of pictures or other visual aids within the profile.

We encourage you to make the designing and completion of the tool a truly collaborative process.

### **Implementation**

Within educational settings it is important that the document is accessible to all stakeholders that may encounter an autistic young person. When considering how to implement this, the groups' view was that signing a declaration after reading the profile was not sufficient to ensure understanding. In cases of temporary staff changes or where a group discussion is scheduled, this would be viewed as adequate. Our suggestion is that the profiles are read and discussed among all staff so that any clarity can be sought, as well ensuring they are understood.

## **GUIDANCE**

### **Implementation continued**

Within health and social care settings this document should be made available for any professional involved in a young person's care. Where contact with these services is temporary or short-term, professionals signing and dating that they have read it would be appropriate.

Should an individual have multi-disciplinary involvement in providing support, we suggest the collaborative reading and discussion of the one-page profile is completed (it may be best suited to align with the annual review processes).

### **Innovation**

It is suggested that individuals have a dialogue with settings to define how the profile will be implemented. We strongly support the use of innovative and technological approaches to ensure one-page profiles are accessible.

The templates provided in the appendix give a visual representation of a document that may be used, though the subtitles could be transferred to other mechanisms to present the information.

*One of the favoured suggestions from the group was using QR codes to provide the information contained on the one-page profile (with appropriate password protection). This could be a useful mechanism for all young people rather singularly for individuals with additional needs.*

### **Embedding**

To ensure the tool remains useful, it is important that it is viewed as a working document that all stakeholders can access. When considering completing the profile, ensuring stakeholders are given guidance and appropriate support to input into its content is important.

It is suggested that for individuals aged 13 or over, the profile is reviewed at least once a year, potentially alongside the annual review. When this occurs, the profile should contain an accurate record of the date as well as the date when the next review should be completed by.

## GUIDANCE

### Embedding continued

Though it is important that an autistic person, or other stakeholder, can request a review of the document at any time. This review should be as soon as feasible to do so. Should a professional seek to review the document, other stakeholders should be informed and given the opportunity to contribute.

*This stems from reports of decisions being made without parents or autistic individuals being consulted. Further, some stakeholders felt that there was not enough guidance about what information would be needed and how to complete the profile. It is crucial that all stakeholders have access to the latest version of the profile at any given time.*

### Training

Part of embedding the guidance provided in this document we felt it important to include some simple tests and activities that can be undertaken to self-reflect how profiles get completed in a specific setting or profession. These included some that stakeholders had personally experienced and felt would be beneficial.

- Utilising current example profiles, test with other involved professionals by removing identifiable information (such as picture/name) and seeing if someone else can identify who it is about. *A good profile should be easily identifiable.*
- Make a personal one-page profile and see if colleagues can identify who it is for. *Similarly, to the first activity.*

Whilst these activities are supported, they are embedded within a wider societal and cultural "shift" of inclusion, equality, and diversity.

### Topic areas and prompts

Through discussions with stakeholders, several topics and possible sections were identified. Whilst this is not exhaustive, they are suggested as a starting point when constructing a one-page profile. Each topic or theme has a description as well as some questions to generate information that may be included. Some subtitles may not be applicable, and the profile should be adapted to the individuals' needs.

*The questions are an example of the type of prompting and collaboration and we encourage stakeholders to develop and add to these (such as using other participatory tools).*

## TOPIC AREAS, PROMPTS AND QUESTIONS

### Overview

Topic	Description	Questions
Photo (optional)	Engaging with the individual so that their voice is central.	<i>Do you want a photo of you on your profile? Which picture would you like?</i>
Name (known as)	Support an individual's preference and act as building a rapport.	<i>How do you want to be referred to?</i>
Pronouns (optional)	Stakeholders completing may decide if this is needed.	<i>How do you want to be referred to?</i>
Diagnoses (optional)	Including any other diagnosis that may be relevant. An individual may prefer to have this on.	<i>Would you want any diagnoses included? How would you like them to be described?</i>
Language	Ensure communication is in the language preferred by the individual.	<i>Would you prefer to communicate in English or Welsh? Do you find it easier to communicate in English or Welsh?</i>
Safe space	Location (within setting).	<i>Where would you like to go should you need to calm down? What type of thing would be useful for this space to be like?</i>
Safe / trusted person	There may need to be one within setting and one external such as family.	<i>If you were starting to feel stressed or uncomfortable, who would you prefer to speak to?</i>

## TOPIC AREAS, PROMPTS AND QUESTIONS

### Overview

Topic	Description	Questions
Any medical alerts	Include links to other documents.	<i>Does this individual have any plans or information that would be needed to be accessed?</i>
Things I am good at / facts about me	Optional – role to act as conversation starter. Also, to give professionals an insight into discussion topics.	<i>What do you like doing in your spare time? What would you like other people to know about you? What things do you know a lot about?</i>
Other key information	Avoid 'putting foot in it'.	<i>Is there anything else you want to have on your profile?</i>

### Communication

Topic	Description	Questions
Preferences	e.g., written/verbal.	<i>If someone is giving you instructions, how would you prefer them to do this? If someone wants to talk to you and ask your opinion, how would you like them to do that? How would you like to get feedback or praise?</i>
Eye contact	e.g., uncomfortable but able to do it, variable etc.	<i>This may involve a discussion with stakeholders.</i>

## TOPIC AREAS, PROMPTS AND QUESTIONS

### Communication

Topic	Description	Questions
Instructions	This can help ensure an individual gets the information needed.	<i>If someone needs you to do something, how do you want that information? Spoken, written? It may need a discussion with stakeholders about specific strategies.</i>
Processing	Such as topics of executive functioning and Theory of Mind. Included information should be relevant for the individual rather than generic statements associated with autism.	<i>When you need to decide, what can help? If someone asks you a question, how long should they give you to answer? This may need to include discussions with stakeholders to identify specific information.</i>

### Anxiety / Stressors

Topic	Description	Questions
Triggers	Something that can sharply increase anxiety or discomfort.	<i>When you have felt overwhelmed in the past, was there anything that caused it? Discuss this with stakeholders and be as specific as possible.</i>
Effect on communication	Levels of communication can vary depending on other factors. It is important to recognise how an individual may communicate when under stress and how to overcome this.	<i>When you don't feel like talking, how can you let someone know what you need? If you feel stressed, is talking harder than usual?</i>

## TOPIC AREAS, PROMPTS AND QUESTIONS

### Anxiety / Stressors continued

Topic	Description	Questions
Signs	These can be physical, behavioural signs. This would require discussions among stakeholders to identify, as well as seeking the individual's views.	<i>When you start to feel worried / anxious, is there anything you do to try and calm yourself down?</i>
Coping strategies	Things that someone can do themselves to help regulate discomfort. These can be useful when trying to prevent an overload or meltdown from occurring.	<i>What helps you calm down? Are there specific things you need? Would a safe space be useful?</i>
How to reduce	'Surface level' things that can be done to reduce anxiety – potential link with sensory.	<i>What is a quick way to help you feel calmer?</i>
Changes	The impact of change on anxiety levels, the importance of routine. Include anything that is part of a daily routine of importance.	<i>If something is going to change, how would you want to know this?</i>

## TOPIC AREAS, PROMPTS AND QUESTIONS

### Environment

Topic	Description	Questions
Sensory needs	General sensory needs in the environment, including those pertinent in the given setting.	<i>If you could design a perfect room, what would it be like? (link in all sensory considerations).</i>
Free time	Times where there are elements of choice, as well as preferences of where to be.	<i>If you could go anywhere to eat your lunch (at school), where would it be? Strategies that are already in place?</i>
Coping strategies	Focusing upon what is needed in environment, what is already in place.	<i>What helps you feel comfortable in ...? Where would you choose to sit? (using sensory considerations to prompt). What are the things that you can do to help you calm down?</i>
Physical needs	e.g., specific chair location, availability of certain resources.	<i>Draw on coping strategies and include clear needs. Do you have a favourite space to sit in the classroom?</i>
Transitions	This focuses upon changing between lessons, new classrooms, or anything else in the environment that has changed.	<i>Are there any coping strategies that should be encouraged?</i>



## TOPIC AREAS, PROMPTS AND QUESTIONS

### Community

Topic	Description	Questions
Friendships / interactions with peers	It is important to recognise the individuals peer networks and understand them.	<i>Do you call anyone at school a friend?</i> <i>Are there things you like doing with other people?</i>
Interests	Likes / dislikes. These can be used as conversational starters, generally topics an individual will be happy to talk about.	<i>What do you enjoy doing?</i> <i>What things do you not like doing?</i> <i>If you could talk about one thing, what would it be?</i>
Relevant adjustments	Include here anything about being vulnerable to manipulation or fear or noncompliance.	<i>This may be embedded within earlier sections.</i> <i>Specific instructions in certain situations, e.g., if you see me doing this, I won't be wanting to, but I won't be able to say no.</i>

### Care needs

Topic	Description	Questions
Any support needed or anything relevant.	These should include anything that affects a young person's care in a general sense (specific information would be provided in medical plan).	<i>How good are you at remembering to drink?</i> <i>Does anyone remind you when you need to eat your lunch?</i> <i>Include a discussion with stakeholders and ensure individual understands the comments made.</i>

## TOPIC AREAS, PROMPTS AND QUESTIONS

### Sensory

Topic	Description	Questions
Impact of sensory needs	General impact of sensory discomfort on anxiety.	
Touch	Feel of fabrics, materials, or other elements of the environment.	
Relevant adjustments	Include here anything about being vulnerable to manipulation or fear or noncompliance.	<i>Discussion among stakeholders to specific preferences or aversions.</i>
Movement	Movement of objects	
Body position	Position in relation to other objects in the environment.	<i>Include links to the environment and specific examples, e.g., lunch times.</i>
Looking	Light sources, visual stimulus.	
Hearing	Sounds, including variation, intensity, volume etc.	
Smell	Specific aversions / smells.	
Taste	Specific foods that may be disliked or liked.	

## TOPIC AREAS, PROMPTS AND QUESTIONS

### Meltdown / Shutdown

Topic	Description	Questions
Signs starting to struggle	Include here signs that may indicate this may happen. Draw on dialogue from various stakeholders.	<i>When you have had a meltdown, what has happened before it?</i> <i>Reflective and retrospective on previous events to highlight signs that could have prompted support/intervention.</i>
What to do	If signs are identified, what should the professional/adult do?	<i>Include here things that may be a distraction, fidgeting, activities the person enjoys.</i>
What not to do	Include things here if they are known not to be useful or to make the situation worse.	<i>Reflective and retrospective.</i>
Signs of meltdown behaviours / non-verbal communications.	How does an individual's communication change when in this 'state'?	<i>Able to talk?</i> <i>Levels of eye contact?</i> <i>Change in behaviours to avoid communication?</i> <i>Language choices?</i> <i>Swearing?</i>

### Masking

Topic	Description	Questions
Specific signs.	Autistic females may be likely to hide their true feelings or experiences, it is useful to know these so that people can be aware that someone may not be ok.	<i>What do you do when you don't want people to ask you if you're ok?</i>

## TOPIC AREAS, PROMPTS AND QUESTIONS

### Other

Topic	Description	Questions
Anything that the individual wants to know, may focus upon previous misconceptions or things they want people to know.	E.g., if you have any questions please ask. E.g., I can't always / I find it hard to ask for help. E.g., just because I look ok doesn't mean I am.	
Links to other documents.	As appropriate. Include list of any referred to in all sections.	

### Permissions

Topic	Description	Questions
Permission for others to communicate on behalf	E.g., my mentor (name) will email on my behalf but copy me into any communications OR my mentor will help me to complete my profile.	<i>Would you like anyone else to be involved in your one-page profile?</i>
'Translator' use	Someone who understands the individual as well as the context who can provide support to enable the learners voice to be heard, translating what may be ambiguous questions into those which can be understood.	<i>Who is this?</i>

## TOPIC AREAS, PROMPTS AND QUESTIONS

### Review

Topic Description Questions

Date of latest review

Date of next review (at latest)

## APPENDICES

### Version 1

Photo	Name (known as)
	Pronouns
	Diagnoses
	Language preferences
Safe space	
Safe person	
Alert – e.g. I have a medical plan	Facts about me
"I may look ok but I may not be"	
COMMUNICATION	Preferences
	Eye contact
	Instructions
	Processing
ANXIETY / STRESSORS	
ENVIRONMENT	

## APPENDICES

### Version 1

COMMUNITY	
CARE NEEDS	
SENSORY	
MELTDOWN / SHUTDOWN	
MASKING	
OTHER	
PERMISSIONS	
Date of latest review	Latest next review date

## APPENDICES

### Version 2

Photo	Name (known as)
	Pronouns
	Diagnoses
	Language preferences
Safe space	
Safe person	
<p>Alert – e.g. I have a medical plan</p> <p>"I may look ok but I may not be"</p> <p>Facts about me</p>	
COMMUNICATION	Preferences
	Eye contact
	Instructions
	Processing

## APPENDICES

Version 2

ANXIETY / STRESSORS	
ENVIRONMENT	
COMMUNITY	
CARE NEEDS	

## APPENDICES

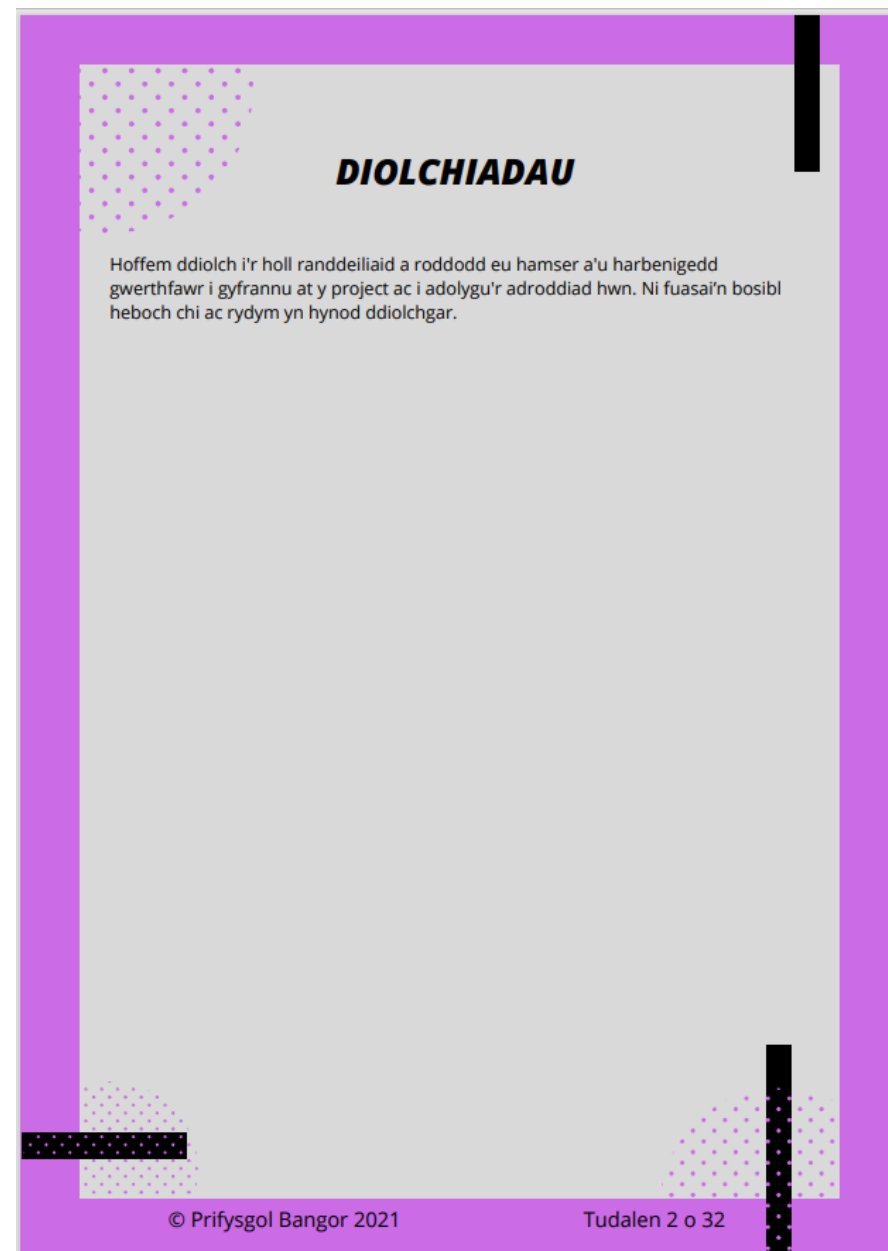
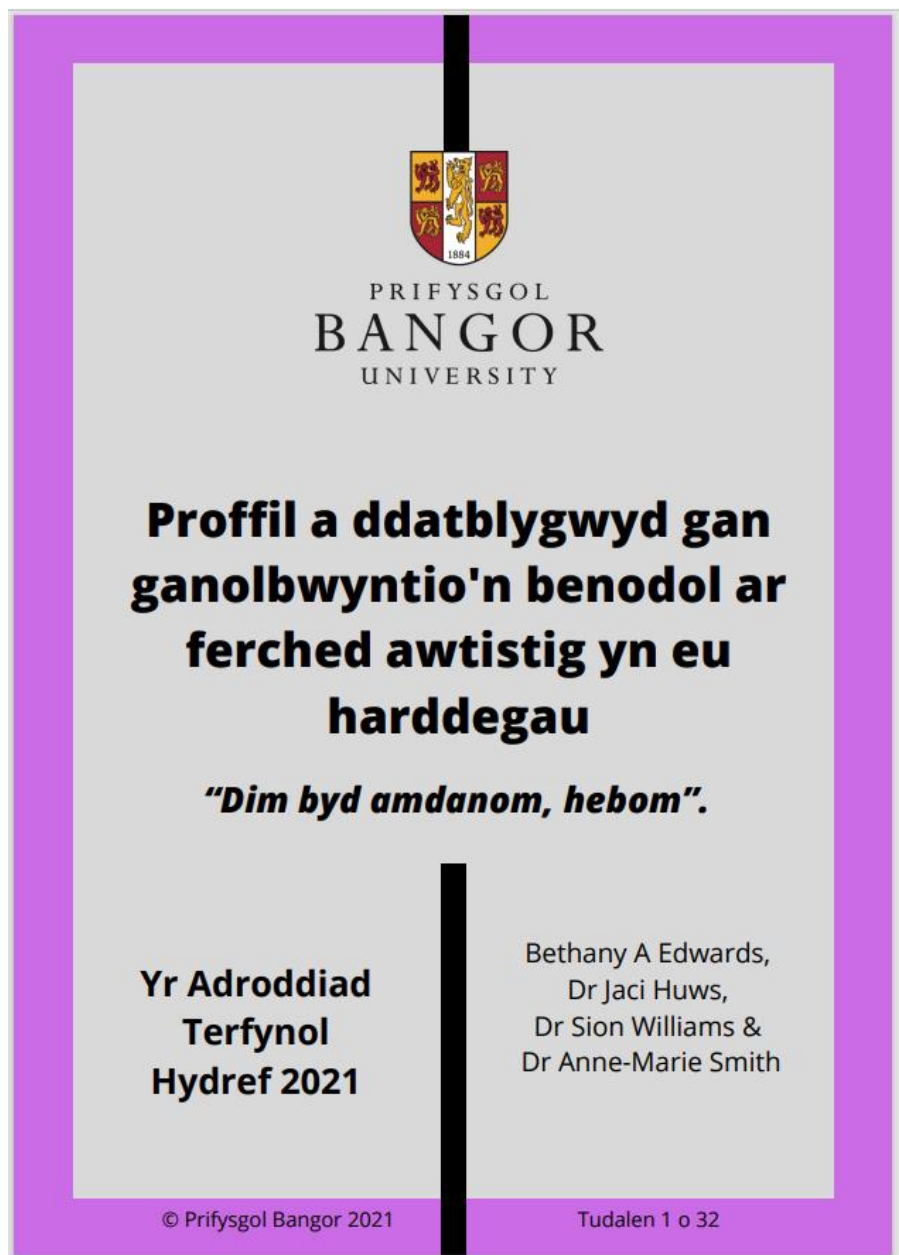
Version 2

SENSORY	
MELTDOWN / SHUTDOWN	
MASKING	
OTHER	

# ***APPENDICES***

**Version 2**

PERMISSIONS	
Date of latest review	Latest next review date



## RHAGAIR

### Cefndir

Hwyluswyd y prosiect hwn gan ymgeisydd PhD ym Mhrifysgol Bangor (yr awdur) mewn cydweithrediad â nifer o randdeiliaid o bob rhan o Gymru.

Mae'r proffil un dudalen yn ddogfen sy'n rhan o'r broses adolygu ar gyfer Plant a Phobl Ifanc yng Nghymru sydd ag Anghenion Dysgu Ychwanegol. Cymerwyd yr wybodaeth am yr offeryn a'r canllawiau o 'Ymarfer sy'n Canolbwyntio ar yr Unigolyn mewn Addysg - canllaw i'r blynyddoedd cynnar, ysgolion a cholegau yng Nghymru' (2015):

“Mae sylfaen cefnogaeth sy'n canolbwyntio ar yr unigolyn, proffil un dudalen yn cynnwys gwybodaeth allweddol am gymeriad, galluedd a thalentau'r unigolyn; beth sy'n bwysig iddyn nhw; a'r ffordd orau o'u cefnogi”.

### Y Dull

Dechreuodd y project hwn trwy werthuso'r offeryn cyfredol, gan ganolbwyntio'n benodol ar ferched awtistig yn eu harddegau. Yn y trafodaethau hynny, daeth yn amlwg bod defnydd rheolaidd ar y proffil un dudalen, er y byddai angen ei addasu at ddefnydd beunyddiol.

Roedd tri cham i'r broses. Cynhaliwyd pob un trwy weithdai cyfranogol ar-lein:

1. Trafodaethau cychwynnol am yr offeryn a thrafod pa wybodaeth i'w chynnwys. Trafodaethau cyffredinol ynghylch profiadau'r rhanddeiliaid o broffiliau un dudalen a meddyliau penodol ynghylch merched awtistig yn eu harddegau.
2. Trafodwyd themâu/awgrymiadau allweddol i'w cynnwys yn yr 'offeryn' newydd yn ogystal â'r canllawiau y byddai eu hangen i fynd ydag ef.
3. Cytuno ynghylch yr offeryn terfynol ymhlith y grŵp.

Bu dau grŵp o randdeiliaid wrthi, sef gweithwyr proffesiynol sy'n ymwneud â merched awtistig, a merched awtistig. Roedd y grŵp proffesiynol yn cynnwys amryw o sectorau, gan gynnwys addysg, gofal iechyd, gofal cymdeithasol, eiriolaeth a'r byd academiaidd. Bu 19 o unigolion yn cymryd rhan.

<https://llyw.cymru/sites/default/files/publications/2019-01/ymarfer-sy-n-canolbwyntio-ar-unigolion-mewn-addysg-canllaw-ar-gyfer-blynyddoedd-cynnar-ysgolion-a-cholegau-yng-nghymru.pdf>

## RHAGAIR

### Canfyddiadau

Trwy'r broses gydweithredol, deallwyd nad yw'r offeryn fel y mae yn briodol i'w ddefnyddio bob dydd. Hefyd, disgrifiwyd cryn amrywiaeth yn y modd y cawsant eu cwblhau yn y gwahanol leoliadau a'r sectorau daearyddol. Er enghraifft, canfuwyd nad oedd lleoliadau addysgol y brif ffrwd yn eu defnyddio'n briodol, a rhai disgrifiadau'n cyfeirio at y farn mai:

“'ymarfer ticio blychau' (dyfyniad gan randdeiliaid) oeddent”

Penderfynwyd y dylai canllawiau'r project hwn gynnig awgrymiadau a chwestiynau ymarferol i gynorthwyo datblygiad y proffil, ynghyd ag ategu'r angen i bobl awtistig fod yn rhan o'r broses. Nid yw'r cwestiynau hyn yn gynhwysfawr ac argymhellir defnyddio offerynnau eraill fel y disgrifir yn nogfen Llywodraeth Cymru.

Rydym wedi cynnwys rhai meysydd penodol a nodwyd trwy'r project hwn, gyda rhywfaint o gyd-destun a chwestiynau neu awgrymiadau cymwys. Cwblheir yr adroddiad trwy ddarparu ychydig o dempledi a ystyrir yn addas ar gyfer proffil da un dudalen.

Dylid creu proffil un dudalen i unigolyn i adlewyrchu ei anghenion orau, er ein bod yn cydnabod ei bod yn ddefnyddiol i weithwyr proffesiynol gael strwythur a chynllun adnabyddadwy i'r ddogfen i'w gwneud hi'n hawdd troi ati. Teimlai'r grŵp rhanddeiliaid hefyd ei bod yn bwysig cynnwys gwybodaeth am weithredu ac adolygu'r offeryn. Yn benodol, wrth sicrhau ei fod yn cael ei ddefnyddio yn y ffordd fwyaf effeithiol.

### Rhagor o wybodaeth

I gael mwy o wybodaeth am gynnwys y ddogfen hon, cysylltwch â Bethany Edwards.

E-bost: [edu4a3@bangor.ac.uk](mailto:edu4a3@bangor.ac.uk)



## CEFNDIR

### Pwrpas proffil un dudalen

Pwrpas y fersiwn hon o'r proffil yw sicrhau y gellir cefnogi merched awtistig yn eu harddegau (ynghyd ag unigolion eraill sydd ag anghenion dysgu ychwanegol) mewn addysg, iechyd a gofal cymdeithasol. Trwy brofiadau helaeth y rhanddeiliaid o'r boblogaeth hon, nodwyd themâu a meysydd pwnc penodol a allai fod yn berthnasol ac y mae angen eu cynnwys. Nodwyd yn benodol efallai na fydd yn hawdd adnabod yr wybodaeth sydd angen mynd ar y dogfennau hyn.

Felly, rydym yn ategu'r angen i hon fod yn broses gydweithredol gyda deialog agored rhwng yr unigolyn awtistig, y teulu, a'r gweithwyr proffesiynol mewn lleoliad.

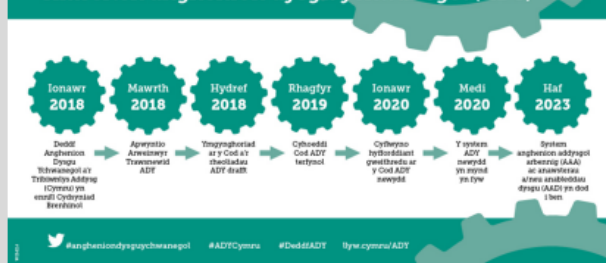
### Rhaglen trawsnewid Anghenion Dysgu Ychwanegol (ALN)

Pasiwyd Deddf Anghenion Dysgu Ychwanegol a'r Tribiwnlys Addysg (Cymru) gan y Cynulliad Cenedlaethol fis Rhagfyr 2017 a chafodd Gydsyniad Brenhinol fis Ionawr 2018. Mae'n cynnwys rheoliadau a chod ADY.

### Beth sy'n newid?

Bydd y system yn troi'r gwahanol systemau sy'n ymwneud ag anghenion addysgol arbennig (AAA) ac anawsterau a/neu anableddau dysgu (AAD) yn un system sy'n cefnogi dysgwyr o 0 i 25 sydd ag ADY.

### Amserlen anghenion dysgu ychwanegol (ADY)



I gael mwy o wybodaeth am hyn, dilynwch y cyswllt hwn:  
[https://llyw.cymru/rhaglen-trawsnewid-anghenion-dysgu-ychwanegol?\\_ga=2.17220473.1344746141.1635005770-1656209211.1635005770](https://llyw.cymru/rhaglen-trawsnewid-anghenion-dysgu-ychwanegol?_ga=2.17220473.1344746141.1635005770-1656209211.1635005770)

## CEFNDIR

### Cysyniadau allweddol - cymdeithasol a diwylliannol

Fel rhan o weithredu'r fersiwn hon o'r proffil, ystyriwyd ei bod yn bwysig rhoi peth o gefndir rai o'r cysyniadau. Nid yw'r rhain yn benodol i ferched awtistig; fodd bynnag, maent yn deillio o'r newid diwylliannol y nodwyd bod ei angen i gynnal yr arferion gorau.

### Confensiwn y Cenhedloedd Unedig ar Hawliau Pobl ag Anableddau (CRPD)

Mae nifer o egwyddorion cyffredinol i'r confensiwn hwn, gan gynnwys:

1. Parch at urddas cynhenid, annibyniaeth unigol gan gynnwys y rhyddid i wneud eich dewisiadau eich hun, ac annibyniaeth pobl.
2. Peidio â gwahaniaethu
3. Cyfranogiad a chynhwysiant llawn ac effeithiol mewn cymdeithas.
4. Parchu gwahaniaeth a derbyn pobl sydd ag anableddau fel rhan o amrywiaeth ddynol a dynoliaeth.
5. Cyfle Cyfartal
6. Hygyrchedd
7. Cydraddoldeb rhwng dynion a merched.
8. Parch at alluoedd esblygol plant ag anableddau a pharch at hawl plant ag anableddau i warchod eu hunaniaethau.

Hefyd, yn gysylltiedig â'r adroddiad hwnnw, mae erthygl 24, sy'n canolbwyntio ar addysg, yn nodi rhai pwyntiau:

- 2c) Darperir yn rhesymol ar gyfer gofynion yr unigolyn.
- 2d) Mae pobl sydd ag anableddau'n derbyn y gefnogaeth sy'n ofynnol, o fewn y system addysg gyffredinol, i hwyluso eu haddysg yn effeithiol.
- 2e) Darperir mesurau cefnogaeth unigol effeithiol mewn amgylcheddau sy'n gwneud yn fawr o ddatblygiad academiaidd a chymdeithasol, yn unol â'r nod o gynhwysiant llawn.

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>

## CEFNDIR

### Cynhwysiant, cydraddoldeb ac amrywiaeth

Mae amrywiol ddiffiniadau o'r termau hyn yn bodoli. Cytunwyd ar y ddealltwriaeth hon trwy drafodaethau grŵp:

Mae cynhwysiant yn hawl ddynol i bawb. Mae'n cynnwys mynediad cyfartal a chyfleoedd i bawb, er efallai na fydd y ffordd y caiff y rheini eu cyflawni neu'u cyrchu yr un peth i bawb. O ystyried cynhwysiant, mae'n bwysig cydnabod y rhwystrau y mae pobl yn eu hwynebu o ran ymaddasu ac o ran llywio'u hynt er mwyn sicrhau y caiff yr hawl ddynol hon ei diwallu.

Mae'n bwysig nodi hefyd bod cynhwysiant yn rhychwantu pob digwyddiad a phroses, er enghraifft, sicrhau bod y prosesau adolygu'n hygyrch i unigolion, eu teuluoedd a gweithwyr proffesiynol. Mae ecwiti'n mireinio'r diffiniad hwnnw fel dull sy'n sicrhau mynediad i'r un cyfleoedd, ynghyd â chynabod bod mantais a rhwystrau'n bodoli.

Yn syml ddigon, amrywiaeth yw presenoldeb gwahaniaeth mewn lleoliad neu amgylchedd, sy'n bod fel rhywbeth ar y cyd yn hytrach nag yn unigol.

### Ymwybyddiaeth

Er i'r grŵp nodi pwysigrwydd hyfforddiant ynghylch gwahanol anghenion ychwanegol a strategaethau cefnogi, nodwyd bod angen i hynny fod yn ychwanegol at ymwybyddiaeth ddiwylliannol ehangach o wahaniaeth a'r amrywiaeth sydd yn y gymuned. Mae ymwybyddiaeth hefyd yn gosod unigolion fel arbenigwyr yn eu bywydau eu hunain, ac o'r herwydd, eiriolwyd dros gyfranogiad yn yr hyfforddiant neu'r canllawiau a roddir i weithwyr proffesiynol a rhanddeiliaid.

Dylai ymgorffori ymwybyddiaeth ymhlith y rhanddeiliaid fod yn proses barhaus, a rhaid ei hadolygu a myfyrio yn ei chylch dros amser. Dylai gweithwyr proffesiynol chwarae rhan weithredol wrth gynyddu eu hymwybyddiaeth a'u gwybodaeth.

### Cyfranogi a Chydweithio

I gwblhau proffil un dudalen a sicrhau'r effaith fwyaf, mae'n hanfodol bod y rhanddeiliaid yn cyfranogi ac yn cydweithio. Rhaid hefyd sicrhau bod yr holl rhanddeiliaid yn cael eu hystyried yn gyfartal.

## CEFNDIR

### Cyfranogi a Chydweithio

Yn y tabl isod, disgrifir hynny yn nhermau'r camau y mae hynny'n eu cynnwys:

#### Rhoi gwybodaeth

Rhoi'r wybodaeth angenrheidiol i'r unigolion, mewn fformat sy'n hygyrch. Dylai'r wybodaeth honno fod yn gytbwys ac yn wrthrychol er mwyn medru gwneud penderfyniad. Bydd angen diweddarau'r cam hwn yn barhaus fel bo'n briodol gydag unrhyw newidiadau neu ddatblygiadau.  
*O roi gwybodaeth i'r rhanddeiliaid rhaid rhoi amser iddynt wneud penderfyniad i sicrhau bod y penderfyniad yn gytbwys.*

#### Ymgynghori

Trin a thrafod pob adborth a geir oddi wrth amrywiol rhanddeiliaid trwy ddulliau hygyrch sy'n eu hystyried yr un mor ddilys â'u gilydd. Dylai hon fod yn broses barhaus ac nid ar un pwynt amser.  
*Dylai canlyniadau a goblygiadau'r ymgynghoriadau fod yn glir ac ar gael i'w gweld. Mewn unrhyw ddatblygiadau, dylid nodi rôl yr ymgynghoriadau.*

#### Cynnwys Pawb

Gweithio'n uniongyrchol â'r rhanddeiliaid trwy gydol y prosesau er mwyn annog ymgysylltiad. Dylai hynny hefyd gynnwys ymwneud â rhanddeiliaid newydd. Mae'r ymwneud hwnnw hefyd yn canolbwyntio ar ddeall ac ystyried yr amrywiol safbwyntiau. Rhaid cynnwys pawb mewn modd sy'n ymateb i anghenion y rhanddeiliaid a rhaid gwneud hynny ymhob cam o'r prosesau sy'n ymwneud â gwneud penderfyniadau.  
*Dylid cyflwyno dehongliadau o'r safbwyntiau a fynegir i'r rhanddeiliaid fedru cytuno yn eu cylch.*

#### Cydweithred u

Partneriaeth gyda'r holl rhanddeiliaid ym mhob agwedd ar wneud penderfyniadau. Dylai hynny hefyd ystyried y dewisiadau sydd gan unigolion, a lle bo hynny'n bosibl, dylid blaenoriaethu'r rheini.

#### Grymuso

Mae hyn yn cynnwys grymuso unigolion i gymryd rhan yn y prosesau hyn, a gallu mynegi barn yn ddilyffethair heb ofni cael eu collfarnu. Bydd ymgorffori hyn yn y gymdeithas o fudd i'r prosesau eraill a drafodir.  
*Awgrymw'n er mwyn grymuso pobl awtistig yn llawn y dylid hyrwyddo eu rôl fel arbenigwyr yn eu bywydau eu hunain.*

## CEFNDIR

### Cysyniadau allweddol - cyd-destunol

Yn ychwanegol at y cysyniadau ehangach a ddisgrifiwyd, bu'r rhanddeiliaid yn adfyfrio ynghylch y derminoleg a'r cysyniadau sy'n ymwneud yn benodol â'r grŵp hwn o unigolion nad ydynt bob amser yn cael eu deall. Er bod llawer o lenyddiaeth yn ymwneud â'r rhain, dywedodd y rhanddeiliaid y byddai'n well ganddyn nhw eu disgrifio yn hytrach na thynnu ar adroddiadau eraill.

### Sbectrwm

Gellir cysylltu'r term hwn â'r broses ddiagnostig (Cyflwr Sbectrwm Awtistiaeth), er ei bod yn bwysig cydnabod ystyr y term mewn bywyd beunyddiol. Mae pawb yn unigryw, a chanddynt gryfderau yn ogystal â meysydd i'w gwella. Yr hyn ydyn nhw a sut maen nhw'n ymgwyflwyno sy'n gwneud unigolyn yn unigryw, ac yn aml rhoddir hynny ar sbectrwm. Mae pobl awtistig yn ffitio ar y sbectrwm hwnnw.

Hefyd, mae pobl awtistig yn ymgwyflwyno mewn gwahanol ffyrdd ar sbectrwm mwy penodol. Yn hanesyddol, defnyddir termau fel 'gweithredol' (functioning) bob pen i'r sbectrwm, ond nid yw'r grŵp o blaid y fath ieithwedd. Mae ystyriaethau sy'n ymwneud â chyfathrebu, gallu cymdeithasol a dewisiadau synhwyraidd yn rhan o'r sbectrwm. Nid yw'r safle ar y sbectrwm yn statig, oherwydd gall ffactorau ehangach, fel gorbryder, ddylanwadu ar brofiadau'r unigolyn. Er enghraifft, efallai y gall yr unigolyn ateb y ffôn un diwrnod, ac yna ar ôl diwrnod hir yn y gwaith a newid yn ei drefn arferol, efallai na fydd yn gallu gwneud hynny ar ddiwrnod arall. Dylai'r proffil anelu at gyflwyno'r amrywioldeb hwnnw, gyda 'sbardunau' ac 'arwyddion' unigol y bydd gweithwyr proffesiynol yn ymwybodol ohonynt.

### Ymgwyflwyno

Yn sgil ystyriaethau o 'sbectrwm', mae'r ymgwyflwyniad yn disgrifio sut mae unigolyn yn cael ei weld gan y byd a'r rhai o'u cwrpas. Unwaith yn rhagor, mae hyn yn aml yn tynnu ar syniadau o weithredu.

Gall hynny amrywio ac yn aml dim ond am bynciau 'amlwg' neu 'ymddygiadol' y caiff ei drafod. Awgrymwn, er bod hyn yn bwysig, ei bod yr un mor werthfawr gallu deall yr elfennau hynod gynnil y mae'r proffil hwn yn eu nodi. Gall yr ymgwyflwyniad hefyd amrywio gan ddibynnu ar yr amgylchedd a lefel pryder yr unigolyn.

## CEFNDIR

### Ymgwyflwyno

Teimlwn mai pwysigrwydd y pwnc hwn yw bod y proffil yn cynnwys cyfeiriad at ymgwyflwyno pan fo pwrpas iddo, fel:

- Sut beth yw 'ddiwrnod da/arferol'.
- Arwyddion bod rhywun yn dechrau gwegian.
- Sut beth yw chwalfa/cau i lawr.

### Cuddio / Celu

Gellir synied am guddio neu gelu o dan ddau brif faes; cuddio heriau neu anghysur a mabwysiadu persona neu 'act' newydd i geisio cadw at y 'normau cymdeithasol' tybiedig.

1. Gall hynny gynnwys ceisio peidio â gwingo, gwneud ystumiau bwriadol â'r wyneb, neu ddefnyddio strategaethau a ddysgwyd er mwyn ceisio cuddio'r rheini.
2. Ar ôl iddynt weld rhyngweithio cymdeithasol llwyddiannus, neu ymddygiad sydd i'w weld yn boblogaidd, gallai unigolion eu copïo a'u hailadrodd gan obeithio am yr un canlyniadau. Gall hyn arwain at ansicrwydd ynghylch eu hunaniaeth eu hunain neu a yw pobl yn eu hoffi oherwydd eu persona ynteu nhw eu hunain.

Nid yw hyn yn gyfyngedig i ferched awtistig, er y nodwyd ei fod yn fwy cyffredin a dwys ymhlith y grŵp hwnnw. Roedd profiadau'r rhanddeiliad, yn benodol y grŵp awtistig, yn ategu hyn ac yn nodi'r cymhlethdodau sy'n anodd eu hesbonio.

“er cymaint y mae rhywun yn deall awtistiaeth yn dda, oni bai eu bod yn awtistig eu hunain ni allant fyth ddeall yn llawn” (dyfyniad cyfranogwr).

### Ysgogi

Mae is-set o ymddygiadau ailadroddus, y cyfeirir atynt yn nodweddiadol fel ysgogi (ymddygiadau hunanysgogol), yn rhan o ddatblygiad pob unigolyn, er y gall y rheini fod yn ddwysach i bobl awtistig.

## CEFNDIR

### Ysgogi

Mae diben y rheini'n cynnwys:

- Maen nhw'n teimlo'n dda,
- Maen nhw'n tawelu pryder,
- Ymwybyddiaeth o'ch cyrff eich hun,
- Helpu ffocws / canolbwyntio,
- Delio â gorlethu (synhwyrâu/emosiynau).

Gall yr un ymddygiad gyflawni pwrpas gwahanol i bawb, yn ogystal â bod yn wahanol ar wahanol adegau, gan ddbynnu ar yr amgylchedd ehangach.

Mae'n heriol iawn rhwystro'r rhain ac oherwydd y pwrpas sydd iddynt, gallai arwain at brofiadau emosiynol neu gorfforol negyddol eraill. Gall fod canlyniadau negyddol hefyd i bobl awtistig, megis ymdeimlad o fod yn od ymysg cyfoedion a chosb oherwydd tybiaeth o ddiffyg ymgysylltiad.

### Gorbryder

Mae gorbryder yn gyffredin ymysg pobl awtistig, ac mae gan bawb sbardunau a dulliau ymdopi gwahanol.

Trwy drafod, gwelir rhai pynciau cyffredin gan gynnwys:

- ansicrwydd a newid,
- sbardunau synhwyradd,
- sefyllfaoedd cymdeithasol,
- disgwyliadau a phwysau.

Gall gorbryder hefyd fod yn ffactor sy'n cyfrannu at lethu a chwalfa. Mae dwyster y gorbryder yn dibynnu ar y pwnc, yn ogystal â sbardunau cronus dros gyfnod. Mae'n bwysig deall effaith gorbryder er mwyn meithrin perthynas, a dyna pam mae ar ddechrau'r proffil.

## CEFNDIR

### "Cyfieithydd"

Yn ystod y gweithdai, cododd y term hwn wrth ddisgrifio gallu unigolyn i gyfrannu at drafodaethau a phrosesau sy'n ymwneud â gwneud penderfyniadau. Fe'i disgrifiwyd fel rhywun a all gyfleu'r wybodaeth i'r unigolyn, yn ogystal â cheisio'r eglurder y bydd ei angen i wneud penderfyniad.

Mewn sefyllfa sy'n peri gorbryder, fel adolygiad, dywedwyd bod defnyddio cyfieithydd yn cynnig sicrwydd a'i fod yn dwyn y pwysau o orfod cofio popeth a drafodir. Mae'n bwysig nodi y cafwyd profiadau cadarnhaol gyda chyfieithwyr lle'r oedd cyd-ddealltwriaeth o'r rôl, perthynas dda a chyfathrebu da, yn ogystal â digon o amser i gwblhau'r broses heb wneud rhag-benderfyniadau.

Trafodwyd rôl eiriolwyr, ond temlai'r rhanddeiliaid mai'r dybiaeth oedd nad oedd unigolyn yn ymwybodol o'r hyn oedd orau. O'i gymharu, ystyrir bod cyfieithydd yn fwy cadarnhaol, megis proses hidlo.

“*Trafodwyd sut roedd cyfieithydd yn aml yn “berson diogel/dibynadwy” (dyffyniad cyfranogwr).*”



## CANLLAWIAU

### Hyblygrwydd

Proffil un dudalen ydi o, ac efallai nad oes digon ar adegau. Byddem yn eich cynghori i ddefnyddio mwy nag un dudalen, yn hytrach na lleihau'r wybodaeth neu newid y cyflwyniad.

Canllaw yn unig yw hwn, ac rydym yn annog unigolion a gweithwyr proffesiynol i ddefnyddio eu barn a'u profiad eu hunain i benderfynu a yw rhywbeth am gael ei gynnwys yn y ddogfen ai peidio.

### Gwedd y dudalen

Er mwyn sicrhau y bydd y ddogfen yn parhau'n hygyrch ac yn fuddiol, lluniasom rai awgrymiadau wrth greu'r ddogfen. Yn ogystal, rydym wedi darparu cynlluniau posib a allai fod yn fan cychwyn wrth wneud proffil.

1. Defnyddiwch iaith glir sy'n hawdd ei deall.
2. Defnyddiwch flychau a nodweddion gweledol eraill i amrywio'r testun.
3. Defnyddiwch bwyntiau bwled i grynhoi gwybodaeth.
4. Ystyriwch ddefnyddio lluniau neu gymhorthion gweledol eraill yn y proffil.

Rydym yn eich annog i wneud dylunio a chwblhau'r offeryn yn broses wirioneddol gydwethredol.

### Gweithredu

Mewn lleoliadau addysgol mae'n bwysig bod y ddogfen ar gael yn hwylus i bawb sy'n debygol o ddod ar draws person ifanc awtistig. O ran sut mae gweithredu hynny, barn y grwpiau oedd nad oedd llofnodi datganiad ar ôl darllen y proffil yn ddigon i sicrhau dealltwriaeth. Mewn achosion o newidiadau i'r staff dros dro neu lle mae trafodaeth grŵp yn yr arfaeth, byddai hynny'n ddigonol. Ein hawgrym yw bod y proffiliau'n cael eu darllen a'u trafod ymhlith yr holl staff er eglurder, yn ogystal â sicrhau bod pawb yn eu deall.

## CANLLAWIAU

### Gweithredu

Mewn lleoliadau iechyd a gofal cymdeithasol dylai'r ddogfen hon fod ar gael i bob gweithiwr proffesiynol sy'n ymwneud â gofal person ifanc. Os yw'r cyswllt â'r gwasanaethau hynny'n rhywbeth dros dro neu'n fyrhoedlog, byddai'n briodol i weithwyr proffesiynol ei llofnodi a'i dyddio i ddangos eu bod wedi ei darllen.

Os oes gan unigolyn ran amlddisgyblaethol yn narpariaeth y gefnogaeth, awgrymwn iddynt gyd-ddarllen a chyd-drafod y proffil un dudalen (efallai y byddai'n addas iawn petai hynny'n cyd-daro â'r prosesau adolygu blynyddol).

### Arloesi

Awgrymir i'r unigolion gynnal deialog gyda'r lleoliadau i ddiffinio sut y caiff y proffil ei weithredu. Rydym yn bleidiol iawn i ddefnyddio dulliau arloesol a thechnolegol i sicrhau bod proffiliau un dudalen yn hygyrch.

Mae'r templedi sydd yn yr atodiad yn rhoi cynrychiolaeth weledol o ddogfen y gellid ei ddefnyddio, er y gellid trosglwyddo'r is-deitlau i fecanweithiau eraill i gyflwyno'r wybodaeth.

*Roedd y grŵp o blaid defnyddio codau QR i ddarparu'r wybodaeth sydd yn y proffil un dudalen (gyda chyfrinair priodol er diogelwch). Gallai hwnnw fod yn fecanwaith defnyddiol i bob person ifanc yn hytrach nag yn rhywbeth i unigolion sydd ag anghenion ychwanegol yn unig.*

### Ymgorffori

Er mwyn sicrhau bod yr offeryn yn parhau i fod yn ddefnyddiol, mae'n bwysig ei hystyried yn ddogfen weithredol y gall yr holl randdeiliaid ei chyrchu. Wrth ystyried cwblhau'r proffil, mae'n bwysig sicrhau bod rhanddeiliaid yn cael arweiniad a chefnogaeth briodol i gyfrannu ato.

Awgrymir, ar gyfer unigolion 13 oed neu hŷn, y dylid adolygu'r proffil o leiaf unwaith y flwyddyn, o bosibl ochr yn ochr â'r adolygiad blynyddol. Os digwydd hynny, dylai'r proffil gynnwys cofnod cywir o'r dyddiad yn ogystal â'r dyddiad y dylid cynnal yr adolygiad nesaf.

## CANLLAWIAU

### Ymgorffori

Er ei bod yn bwysig bod unigolyn awtistig, neu randdeiliad arall, yn cael gofyn am adolygiad o'r ddogfen ar unrhyw adeg. Dylid cynnal yr adolygiad hwn cyn gynted ag sy'n bosib. Pe bai gweithiwr proffesiynol am adolygu'r ddogfen, dylid hysbysu'r rhanddeiliaid eraill a rhoi cyfle iddynt gyfrannu.

*Mae hynny'n deillio o adroddiadau o benderfyniadau a wnaed heb ymgynghori â'r rhieni na'r unigolion awtistig. Hefyd, teimlai rhai rhanddeiliaid nad oedd digon o ganllawiau ynghylch pa wybodaeth fyddai ei hangen a sut i gwblhau'r proffil. Mae'n hanfodol bod gan bob rhanddeiliad fynediad i fersiwn ddiweddaraf y proffil ar unrhyw adeg benodol.*

### Hyfforddiant

O ran ymgorffori'r canllawiau sydd yn y ddogfen hon, teimlem ei bod yn bwysig cynnwys rhai profion a gweithgareddau syml y gellid eu cynnal at ddiobenion adfyfrio ynglŷn â sut mae cwblhau proffiliau mewn lleoliad neu broffesiwn penodol. Roedd y rheini'n cynnwys rhai yr oedd y rhanddeiliaid wedi'u profi'n bersonol ac yn teimlo y byddent yn fuddiol.

- Defnyddiwyd broffiliau enghreifftiol cyfredol i wneud profion gyda gweithwyr proffesiynol perthnasol eraill trwy gael gwared ar wybodaeth y gellid adnabod rhywun wrthi (fel lluniau/enwau) a gweld a all rhywun arall adnabod rhywun. Dylai proffil da fod yn hawdd ei adnabod.
- Gwnewch broffil un dudalen bersonol a gofynnwch a all eich cydweithwyr adnabod i bwy y mae. Yn yr un modd, ar gyfer y gweithgaredd cyntaf.

Er bod cefnogaeth i'r gweithgareddau hyn, maent wedi'u hymgorffori mewn "shift" cymdeithasol a diwylliannol ehangach o gynhwysiant, cydraddoldeb ac amrywiaeth.

### Meysydd pwnc ac awgrymiadau

Trwy drafodaethau â'r rhanddeiliaid, nodwyd nifer bynciau ac adrannau bosibl. Er nad yw'r rhain yn gynhwysfawr, fe'u hawgrymir fel man cychwyn wrth lunio proffil un dudalen. Mae gan bob pwnc neu thema ddisgrifiad yn ogystal â rhai cwestiynau i gynhyrchu gwybodaeth y gellid ei chynnwys. Efallai na fydd rhai is-deitlau'n berthnasol, a dylid addasu'r proffil at anghenion yr unigolion.

*Mae'r cwestiynau'n enghreifftiau o'r mathau o awgrymiadau a'r cydweithio ac rydym yn annog y rhanddeiliaid i ddatblygu ac ychwanegu atynt (megis defnyddio dulliau cyfranogol eraill).*

## ARDALOEDD PWNC, AWGRYMIADAU A CHWESTIYNAU

### Trosolwg

Pwnc	Description	Cwestiynau / awgrymiadau
Llun (dewisol)	Ymgysylltu â'r unigolyn fel bod eu llais yn ganolog.	<i>A ydych chi eisiau llun ohonoch chi ar eich proffil? Pa lun hoffech chi?</i>
Enw (a adwaenir fel)	Cefnogi dewis yr unigolyn a meithrin perthynas.	<i>Sut ydych chi am gael eich adnabod?</i>
Rhagenwau (dewisol)	Gall rhanddeiliaid sy'n cwblhau benderfynu a oes angen hyn.	<i>Sut ydych chi am gael eich adnabod?</i>
Diagnosau (dewisol)	Gan gynnwys unrhyw ddiagnosis arall a allai fod yn berthnasol. Efallai y byddai'n well gan yr unigolyn petai hwnnw arno.	<i>A fydddech chi am gynnwys unrhyw ddiagnosis? Sut hoffech chi iddynt gael eu disgrifio?</i>
Iaith	Sicrhewch eich bod yn cyfathrebu yn newis iaith yr unigolyn.	<i>A fyddai'n well gennych gyfarthrebu yn Gymraeg neu Saesneg? A ydych chi'n ei chael hi'n haws cyfathrebu yn Gymraeg neu Saesneg?</i>
Man diogel	Lleoliad (o fewn y lleoliad).	<i>Ble hoffech chi fynd pe bai angen i chi dawelu? Beth fyddai'n ddefnyddiol yn y lle hwnnw?</i>
Person diogel / dibynadwy	Efallai y bydd angen un yn y lleoliad ac un allanol fel rhywun o'r teulu.	<i>Petaech chi'n dechrau teimlo dan straen neu'n anghyfforddus, gyda phwy fyddai'n well gennych siarad?</i>

## ARDALOEDD PWNC, AWGRYMIADAU A CHWESTIYNAU

### Trosolwg

Pwnc	Disgrifiad	Cwestiynau / awgrymiadau
Unrhyw rybuddion meddygol	Cynhwyswch gysylltiadau â dogfennau eraill.	<i>A oes gan yr unigolyn hwn unrhyw gynlluniau neu wybodaeth y byddai angen cael mynediad atynt?</i>
Pethau rwy'n dda am eu gwneud / ffeithiau amdanaf	Dewisol - rôl i weithredu fel rhywun sy'n cychwyn sgwrs. Hefyd, i roi cipolwg i weithwyr proffesiynol o'r pynciau trafod.	<i>Beth ydych chi'n ei wneud yn eich amser hamdden?</i> <i>Beth hoffech chi i bobl eraill ei wybod amdanoch chi?</i> <i>Pa bethau ydych chi'n wybodus iawn yn eu cylch?</i>
Gwybodaeth allweddol arall	Osgoi 'rhoi'ch troed ynddi'.	<i>A oes rhywbeth arall yr ydych am ei gael ar eich proffil?</i>

### Cyfathrebu

Pwnc	Disgrifiad	Cwestiynau / awgrymiadau
Dewisiadau	e.e., ysgrifenedig/llafar.	<i>Os oes rhywun yn rhoi cyfarwyddiadau i chi, sut hoffech chi iddynt wneud hynny?</i> <i>Os oes rhywun eisiau siarad â chi a gofyn eich barn, sut hoffech chi iddynt wneud hynny?</i> <i>Sut hoffech chi gael adborth neu ganmoliaeth?</i>
Cyswllt llygaid	e.e., rwy'n anghyfforddus ond yn gallu gwneud, mae'n amrywio ac yn y blaen.	<i>Gallai hyn gynnwys trafodaeth gyda rhanddeiliaid.</i>

## ARDALOEDD PWNC, AWGRYMIADAU A CHWESTIYNAU

### Cyfathrebu

Pwnc	Disgrifiad	Cwestiynau / awgrymiadau
Cyfarwyddiadau	Gall hyn helpu sicrhau bod yr unigolyn yn cael yr wybodaeth sydd ei hangen.	<i>Os oes rhywun angen i chi wneud rhywbeth, sut ydych chi eisiau'r wybodaeth honno? Ar lafar, yn ysgrifenedig? Efallai y bydd angen trafod gyda rhanddeiliaid ynghylch strategaethau penodol.</i>
Prosesu	Megis pynciau fel gweithredu goruchwyliol a Theori Meddwl. Dylai'r wybodaeth a gynhwysir fod yn berthnasol i'r unigolyn yn hytrach na datganiadau generig am awtistiaeth.	<i>Pan fydd angen i chi benderfynu, beth all helpu?</i> <i>Os bydd rhywun yn gofyn cwestiwn ichi, pa mor hir y dylent ei roi ichi ateb?</i> <i>Efallai y bydd angen i hynny gynnwys trafodaethau gyda rhanddeiliaid i nodi gwybodaeth benodol.</i>

### Gorbryder / Straen

Pwnc	Disgrifiad	Cwestiynau / awgrymiadau
Sbardunau	Rhywbeth a all gynyddu gorbryder neu anghysur yn ddifrifawr.	<i>Pan oeddech yn teimlo eich bod wedi'ch llethu yn y gorffennol, a oedd rhywbeth yn achosi hynny?</i> <i>Trafodwch hynny gyda rhanddeiliaid a byddwch mor benodol â phosibl.</i>
Yr effaith ar gyfathrebu	Gall lefelau cyfathrebu amrywio gan ddibynnu ar ffactorau eraill. Mae'n bwysig cydnabod sut y byddai unigolyn yn cyfathrebu ac yntau dan straen a sut mae goresgyn hynny.	<i>Os nad ydych chi yn yr hwyliau i siarad, sut mae rhoi gwybod i rywun beth sydd ei angen arnoch chi?</i> <i>Os ydych chi dan straen, a yw siarad yn anoddach nag arfer?</i>



## ARDALOEDD PWNC, AWGRYMIADAU A CHWESTIYNAU

### Gorbryder / Straen

Pwnc	Disgrifiad	Cwestiynau / awgrymiadau
Arwyddion	Gall y rhain fod yn arwyddion corfforol, ymddygiadol. Byddai angen trafod ymhlith y rhanddeiliaid i'w nodi, yn ogystal â cheisio barn yr unigolyn.	<i>Pan fyddwch chi'n dechrau teimlo'n bryderus / yn orbryderus, a oes rhywbeth rydych chi'n ei wneud i geisio ymdawelu?</i>
Strategaethau ymdopi	Pethau y gall rhywun eu gwneud eu hunain i helpu rheoli anghysur. Gallant fod yn ddefnyddiol wrth geisio gwarchod rhag cael eich gorlethu neu rhag chwalfa.	<i>Beth sy'n eich helpu chi ymdawelu? A oes angen pethau penodol arnoch chi? A fyddai man diogel yn ddefnyddiol?</i>
Sut i leihau	Pethau 'arwynebol' i'w gwneud i leihau pryder - cysylltiad posibl â'r synhwyraidd.	<i>A oes ffordd gyflym o'ch helpu chi ymdawelu?</i>
Newidiadau	Effaith newid ar lefelau gorbryder, pwysigrwydd cadw at drefn arferol. Cynhwyswch unrhyw beth sy'n rhan o'r drefn ddyddiol o ran pwysigrwydd.	<i>Os oes rhywbeth yn mynd i newid, sut byddech chi eisiau gwybod hynny?</i>

## ARDALOEDD PWNC, AWGRYMIADAU A CHWESTIYNAU

### Amgylchedd

Pwnc	Disgrifiad	Cwestiynau / awgrymiadau
Anghenion synhwyraidd	Anghenion synhwyraidd cyffredinol yn yr amgylchedd, gan gynnwys y rhai sy'n berthnasol yn y lleoliad penodol.	<i>Pe gallech chi ddylunio ystafell berffaith, sut brofiad fyddai hynny? (nodwch bob ystyriaeth synhwyraidd).</i>
Amser rhydd	Amserau lle mae elfennau o ddewis, yn ogystal â dewisiadau ble i fod.	<i>Pe gallech chi fynd i unrhyw le i fwyta'ch cinio (yn yr ysgol), ble fyddai hynny? Strategaethau sydd eisoes ar waith?</i>
Strategaethau ymdopi	Gan ganolbwyntio ar yr hyn sydd ei angen yn yr amgylchedd, beth sydd eisoes ar waith.	<i>Beth sy'n eich helpu chi deimlo'n gyffyrddus yn...? Ble byddech chi'n dewis eistedd? (gan ddefnyddio ystyriaethau synhwyraidd fel awgrymiadau). Beth yw'r pethau y gallwch chi eu gwneud i'ch helpu chi ymdawelu?</i>
Anghenion corfforol	e.e., lleoliad penodol y gadair, bod adnoddau neilltuol ar gael.	<i>Tynnu ar strategaethau ymdopi a chynnwys anghenion clir. A oes gennych chi hoff le i eistedd yn yr ystafell ddosbarth?</i>
Pontio	Dyma ganolbwyntio ar newid rhwng gwersi, ystafelloedd dosbarth newydd, neu rywbeth arall yn yr amgylchedd a newidiodd.	<i>A oes unrhyw strategaethau ymdopi y dylid eu hannog?</i>



## ARDALOEDD PWNC, AWGRYMIADAU A CHWESTIYNAU

### Cymuned

Pwnc	Disgrifiad	Cwestiynau / awgrymiadau
Cyfeillgarwch / rhyngweithio â chyfoedion.	Mae'n bwysig cydnabod rhwydweithiau cymheiriad yr unigolion a'u deall.	<i>A oes gennych ffrindiau yn yr ysgol? A oes yna bethau rydych chi'n hoffi eu gwneud gyda phobl eraill?</i>
Diddordebau	Hoff bethau / cas bethau Gellir defnyddio'r rhain i gychwyn sgwrs. Pynciau y bydd unigolyn yn hapus i siarad amdanynt.	<i>Beth ydych chi'n mwynhau ei wneud? Pa bethau nad ydych chi'n hoffi eu gwneud? Pe baech yn gallu siarad am un peth, beth fyddai hwnnw?</i>
Addasiadau perthnasol.	Cynhwyswch yma unrhyw beth am fod yn agored i gael eich trin yn ystrygar neu ofn neu ddiffyg cydymffurfio.	<i>Gellir ymgorffori hyn mewn adrannau cynharach. Cyfarwyddiadau penodol mewn sefyllfaoedd neilltuoel, e.e., os gwelwch chi fi'n gwneud hyn, fyddai' i ddim eisiau gwneud hynny, ond fedra' i ddim ymrwthod.</i>

### Anghenion gofal

Pwnc	Disgrifiad	Cwestiynau / awgrymiadau
Unrhyw gefnogaeth sydd ei hangen neu unrhyw beth perthnasol.	Dylai'r rhain gynnwys unrhyw beth sy'n effeithio ar ofal person ifanc mewn ystyr gyffredinol (byddai gwybodaeth benodol yn cael ei darparu yn y cynllun meddygol).	<i>Pa mor dda ydych chi am gofio yfed? A oes rhywun yn eich atgoffa fod angen i chi fwyta'ch cinio? Cynhwyswch drafodaeth gyda'r rhanddeiliaid a sicrhewch fod yr unigolyn yn deall y sylwadau a wnaed.</i>

## ARDALOEDD PWNC, AWGRYMIADAU A CHWESTIYNAU

### Synhwyrdd

Pwnc	Disgrifiad	Cwestiynau / awgrymiadau
Effaith yr anghenion synhwyrdd	Effaith gyffredinol anghysur synhwyrdd ar orbryder.	
Cyffwrdd	Teimlo ffabrigau, deunyddiau, neu elfennau eraill o'r amgylchedd.	
Perthnasol Addasiadau	Dylech gynnwys yma unrhyw beth am fod yn agored i gael eu trin neu eu hofn neu ddiffyg cydymffurfio.	
Symud	Symud gwrthrychau.	
Safle'r corff	Y safle mewn perthynas â gwrthrychau eraill yn yr amgylchedd.	
Edrych	Ffynonellau golau, ysgogiadau gweledol.	
Clyw	Seiniau, gan gynnwys amrywiad, dwyster, uchder ac yn y blaen.	
Arogl	Cas bethau / arogleuon penodol.	
Blas	Bwydydd penodol y gellir eu casáu neu eu hoffi.	

*Trafodaeth ymhlith y rhanddeiliaid ynghylch eu hoff bethau neu'u cas bethau penodol.*

*Cynhwyswch gysylltiadau â'r amgylchedd ac enghreifftiau penodol, e.e., amser cinio.*

## ARDALOEDD PWNC, AWGRYMIADAU A CHWESTIYNAU

### Chwalfa / Cau Lawr

Pwnc	Disgrifiad	Cwestiynau / awgrymiadau
Arwyddion bod rhywun yn dechrau cael trafferth	Cynhwyswch yma arwyddion a allai ddangos y gallai hynny ddigwydd. Tynnwch ar ddeialog gan amrywiol randdeiliaid.	<i>Pan brofoch chi chwalfa, beth ddigwyddodd cyn hynny?</i> <i>Adfyfrio a meddwl yn ôl am ddigwyddiadau blaenorol i dynnu sylw at arwyddion a allai fod wedi ysgogi cefnogaeth/ymyrraeth.</i>
Beth i'w wneud	Os nodir arwyddion, beth ddylai'r gweithiwr proffesiynol/oedolyn ei wneud?	<i>Cynhwyswch yma bethau a allai dynnu sylw'n ddiangen, gwingo, gweithgareddau y mae'r person yn eu mwynhau.</i>
Beth i beidio â'i wneud	Peidiwch â chynnwys pethau yma os gwyddys nad ydyn nhw'n ddefnyddiol neu'n debygol o waethygu'r sefyllfa.	<i>Adfyfrio a meddwl yn ôl.</i>
Arwyddion o ymddygiadau sy'n arwydd o chwalfa / cyfathrebu'n ddiariau.	Ym mha fodd mae cyfathrebu'r unigolyn yn newid pan mae yn y cyflwr hwnnw?	<i>Yn gallu siarad?</i> <i>Lefelau cyswllt llygad?</i> <i>Newid ymddygiad er mwyn osgoi cyfathrebu?</i> <i>Dewisiadau iaith?</i> <i>Rhegi?</i>

### Celu

Pwnc	Disgrifiad	Cwestiynau / awgrymiadau
Arwyddion penodol.	Efallai y bydd merched awtistig yn debygol o gelu eu gwir deimladau neu brofiadau. Mae'n ddefnyddiol gwybod beth ydynt fel y gall pobl fod yn ymwybodol efallai nad yw rhywun yn iawn.	<i>Beth ydych chi'n ei wneud os nad ydych chi am i bobl ofyn i chi a ydych chi'n iawn?</i>

## ARDALOEDD PWNC, AWGRYMIADAU A CHWESTIYNAU

### Arall

Pwnc	Disgrifiad	Cwestiynau / awgrymiadau
Gall y pethau mae'r unigolyn eisiau eu gwybod ganolbwyntio ar gamsyniadau blaenorol neu bethau mae am i bobl eu gwybod.	e.e., mae croeso i chi ofyn unrhyw gwestiynau. e.e., ni allaf bob amser / rwy'n ei chael hi'n anodd gofyn am help. e.e., nid yw'r ffaith fy mod i'n edrych yn iawn yn golygu 'mod i.	
Cysylltiadau â dogfennau eraill.	Fel bo'n briodol Cynhwyswch restr o'r rhai y cyfeirir atynt ym mhob adran.	
<b>Caniatâd</b>		
Pwnc	Disgrifiad	Cwestiynau / awgrymiadau
Caniatâd i eraill gyfathrebu ar eu rhan	E.e., bydd fy mentor (enw) yn e-bostio ar fy rhan ond yn fy nghopio i mewn i unrhyw ohebiaeth NEU bydd fy mentor yn fy helpu i gwblhau fy mhroffil.	<i>A hoffech chi i rywun arall chwarae rhan yn eich proffil un dudalen?</i>
Defnyddio 'cyfieithydd'	Rhywun sy'n deall yr unigolyn yn ogystal â'r cyd-destun a all ddarparu cefnogaeth fel y clywir llais y dysgwyr, gan wneud cwestiynau amwys yn fwy eglur.	<i>Pwy yw hwn?</i>

# ARDALOEDD PWNC, AWGRYMIADAU A CHWESTIYNAU

## Adolygu

Pwnc

Disgrifiad

Cwestiynau / awgrymiadau

Dyddiad yr  
adolygiad  
diweddaraf:

Dyddiad yr  
adolygiad nesaf  
(fan bellaf)

# ATODIADAU

## Fersiwn 1

Llun	Enw (a adwaenir fel)
	Rhagenwau
	Diagnosau
	Iaith

Man diogel	Person dibynadwy
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Rhybudd – e.e.  
Mae gennyf  
gynllun meddygol

"Efallai fy mod yn  
edrych yn iawn  
ond efallai na  
fyddaf"

Ffeithiau amdanaf

CYFATHREBU	Dewisiadau
	Cyswilt llygaid
	Cyfarwyddiadau
	Prosesu

GORBRYDER / STRAEN	
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AMGYLCHEDO	
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# ATODIADAU

## Fersiwn 1

CYMNED	
GOFAL	
SYNHWYRAIDD	
CHWALEA / CAU LAMR	
CELU	
ARALL	
CANIATÂD	
Dyddiad yr adolygiad diweddaraf	Dyddiad yr adolygiad nesaf (fan bellaf)

# ATODIADAU

## Fersiwn 2

Llun	Enw (a adwaenirfel)
	Rhagenwau
	Diagnosau
	Iaith
Man diogel	
Person dibynadwy	
<p>Rhybudd – e.e. Mae gennyf gynllun meddygol</p> <p>"Efallaif y mod yn edrych yn iawn ond efallaia fyddaf"</p>	
Ffeithiau amdanaf	
CYFATHREBU	Dewisiadau
	Cyswilt llygaid
	Cyfarwyddiadau
	Prosesu

# ATODIADAU

Fersiwn 2

GORBRYDER / STRAEN	
AMGYLCHEDD	
CYMIUNED	
GOFAL	

# ATODIADAU

Fersiwn 2

SYNHWYRAIDD	
CHWALFA / CAU LAWR	
CELU	
ARALL	

# ATODIADAU

## Fersiwn 2

CANIATÂD	
Dyddiad yr adolygiad diweddaraf	Dyddiad yr adolygiad nesaf (fan bellaf)

# ATODIADAU

## Fersiwn 3

AMGYLCHEDD	GORRYDER/STRAEN	CYFATHREBU
ARALL	Llun	CYMLUNED
CELU	Enw (a adreant fel)	GOFAL
	Rhesenwau	SYNHWYRAIDD
	Diagnosau	
	Ialh	
	Person ddyrnadwy	
	Man dogel	
	CHWALFA	

## Appendix 35

# Prifysgol **BANGOR** University RISK ASSESSMENT FORM



<b>Risk Assessment (RA) Title</b> Remember to complete Footer details	<b>Empirical study data collection Risk Assessment</b>	<b>Date RA Created and/or Reviewed</b>	03-11-2020	<b>Version Number</b>	1
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Summary of Activity RA Covers			
<p>A qualitative study to evaluate and develop the 'one-page profile' with key stakeholders for use for autistic teenage girls. Data will be collected through the workshops, which include transcriptions of the discourse within them.</p> <p>Consent will be obtained from a parent/career for participants under 18 prior to any aspect of communication or data collection.</p> <p>Participants will be identified through inclusion criteria, and standardised invitations to participate will be made available.</p> <p>Risk assessment covers the workshops and any communications with participants.</p>			
<b>Location(s) RA Covers</b>	Data collection sites (online)	<b>Person(s) RA Covers</b>	Bethany Edwards
<b>College / Service</b>	College of Human Sciences	<b>School / Section</b>	School of Health Science
<b>RA Assessor(s)</b>		<b>Contact Details</b>	Edu4a3@bangor.ac.uk
<b>Actions to be Reviewed By</b>		<b>Next RA Review Date</b>	Review prior to further study.

**NOTE: Arrangements must be in place to communicate new and / or revised Risk Assessments to relevant persons. Older versions must be removed from use (e.g., Folders, Website, My Bangor, Blackboard, Notice Boards) and filed for future**

Ref no	Risk factor	Stage	Controls to prevent risk	Risk levels	Further action needed?	
					Yes	No
1.	Participant age	The participant	<ul style="list-style-type: none"> <li>• There are no associated risks from taking part in this study, however these have been explored and measures put in place to limit through ethical review process and protocol.</li> <li>• Consent will be obtained as appropriate as well as information being available at a level suitable for the participant.</li> <li>• Consent will be gained from a parent/guardian for participants under 18, as well as these being kept updated with information about dates and times of workshops.</li> <li>• Emergency contact information for all participants will be collected, with participants being informed of when and how this would be used. This will be accessible by both research supervisors.</li> </ul>	<p>a. Low – the risk of negative effects is low. All participants and their parent/career will be provided with an information sheet and will be fully debriefed after the study has taken place.</p> <p>b. Contact details will be provided for the research, project supervisors and head of school should any issues emerge.</p> <p>c. Topics should not include those considered to be sensitive, with group rules being established. All conversations are voluntary, and the nature of contribution can be verbal or through the chat function. Participants will be provided with a summary of each workshop before them.</p> <p>d. There is an emergency contact system in place with clear guidance as to what action should be taken in different circumstances.</p>		
2.	Participant physical and mental health	The participant	<ul style="list-style-type: none"> <li>• All participants under 18 will have had their parents/career's consent obtained before becoming involved in</li> </ul>	<p>a. Physical health – low. There are no risks associated with participation in this study.</p>		



Ref no	Risk factor	Stage	Controls to prevent risk	Risk levels	Further action needed?
			<p>the study. They will consent (or not) to taking part.</p> <ul style="list-style-type: none"> <li>• Details of people to contact should distress occur will be provided.</li> <li>• Information sheets will outline what taking part entails and the topics which may arise.</li> </ul>	<p>b. Mental health – low. Topics may be sensitive, but measures have been put in place to ensure that this is limited. Contribution is optional and contact details will be given should participants experience distress.</p> <p>c. Ethical approval has been granted for this study.</p>	
3.	Informed consent	The participant	<ul style="list-style-type: none"> <li>• To ensure fully informed consent, information sheets will be provided to all participants (including parents of under 18's) prior to their consent, and participants before becoming involved.</li> <li>• These will be available prior to consent being sought.</li> <li>• Participants and/or parents will have the opportunity to ask questions throughout and after the study.</li> </ul>	<p>a. Low – the information sheets provide a lot of information about what will be involved in the study, what the focus is and what possible topics may be discussed.</p> <p>b. All documents provided have been approved by the ethical review process.</p> <p>c. Participations will be reminded of their right to withdraw and that they do not have to participate or contribute in all areas of the study.</p>	
4.	Capacity to consent	The participant	<ul style="list-style-type: none"> <li>• Parental or career consent will be sought prior to introducing the study to the sample (aged under 18).</li> <li>• The information sheet for autistic participants will be using language which is more friendly and clear.</li> <li>• Whilst focusing on a sample considered vulnerable, the information</li> </ul>	<p>a. Low – both individuals and their parents / careers will be able to choose whether they take part (under 18).</p> <p>b. The inclusion of this sample group has been justified.</p>	

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			available and the measures in place to manage risk, such as the established contact, are considered sufficient to prevent risk.	<p>c. A two-stage consent process will limit possible risk associated with capacity.</p> <p>d. Should capacity status change throughout participation, the parent/guardian who provided consent will be able to speak to the research team and withdraw future participation should that be desired.</p>	
5.	History of aggression, behavioural problems etc.	The participant	<ul style="list-style-type: none"> <li>• Ground rules / expectations will be established among participants at the start of workshops.</li> <li>• Researcher will not be alone in online space where data is being completed. A plan of action should such actions occur has been established, including an emergency procedure.</li> </ul>	<p>a. Medium – This risk cannot be deemed low as we have no prior knowledge about participant's behaviours and any similar history.</p> <p>b. May be enhanced during discussions which provoke distress or anxiety, so these this will be monitored more closely during such discussions.</p>	
6.	Language used	The participant	<ul style="list-style-type: none"> <li>• The language used for the participants will be friendly, and the information sheet will be clear.</li> <li>• Materials will be available bilingually to participants.</li> <li>• Participants will have the opportunity to discuss the materials provided and clarify the meaning of any ambiguous text.</li> </ul>	<p>a. Low – meanings of key terminology will be made clear to participants.</p> <p>b. Competency in language, reading or writing are not a pre-requisite or necessary for participation. Individual needs will be considered as appropriate.</p> <p>c. Participants will have access to all documents bilingually, but 'live' discussions will be conducted in</p>	

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			<ul style="list-style-type: none"> <li>Participants and parents will be reminded that they have the right to ask questions and they will be given contact details in order to do so.</li> </ul>	English. This may prevent a low risk should this not be an individual's first language.	
7.	Contact being made face to face (through web-cam)	All	<ul style="list-style-type: none"> <li>Nature of contact will be made clear to participants, namely the use of online technology for workshops.</li> <li>Guidance for the use of online technology will be provided.</li> <li>Safeguarding and emergency procedures have been established, as well as participants being aware of how this may be used.</li> <li>Participants of live discussions will be encouraged to sign in for all aspects of participation, even when not actively participating. This is to ensure their well-being and safety. A clear pathway should someone not do this has been identified.</li> </ul>	<ul style="list-style-type: none"> <li>a. Low risk – parental consent will be obtained prior to participation. The information sheet will clearly outline the nature of the study and that it will involve online contact.</li> <li>b. A document will be shared with details of the structure of live communications as well as guidance on how to access the platform, how to change settings to maintain confidentiality.</li> <li>c. The use of a web cam will be optional for all participants.</li> <li>d. Participants will be asked to not have anyone else within vision of the web cam or screen, as well as being in a place that allows for privacy.</li> </ul>	
8.	Experience, or lack of experience.	The researcher	<ul style="list-style-type: none"> <li>The project is being overseen by two supervisors who can provide advice and guidance as required.</li> <li>The project documents, including the schedules and materials have been</li> </ul>	<ul style="list-style-type: none"> <li>a. Low risk – the risk of negative effect is low as the supervision team are experienced and members of university staff.</li> <li>b. The researcher has previously conducted data collection, as well</li> </ul>	

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			<p>approved during the ethical review process.</p> <ul style="list-style-type: none"> <li>• Contact details for the researcher, supervisors, and head of school are provided should any issues occur.</li> <li>• Time has been taken to outline all procedures and the schedules associated with participation.</li> </ul>	<p>as having personal and professional experiences of individuals who meet the inclusion criteria.</p> <p>c. The researcher has a DBS certification, as well as an understanding of safeguarding and disclosures.</p>	
9.	Personal boundaries	The researcher	<ul style="list-style-type: none"> <li>• As the topic has been chosen by the researcher, as well as being central in the design process, there will not be any personal boundaries crossed.</li> <li>• The positioning of the researcher and the role during participation will be explained and discussed with participants.</li> <li>• Supervision team will be aware of all times and locations of data collection and will provide support as needed.</li> <li>• Researchers diagnosis will be disclosed in Phase 1 with group 1 only (autistic girls) (as appropriate) as it is considered beneficial in obtaining rich data (previous literature limitations focus on participants being more open when they shared a characteristic with the researcher).</li> </ul>	<p>a. Low – the researcher has an invested interest in the topic and is aware of the possible avenues the discussions may take.</p> <p>b. The researcher has support in place via a mentor to manage the social and online processes involved with data collection.</p> <p>c. The researcher will ensure that their support network, including personal tutor, are aware when data collection is taking place in order to monitor any possible harm arising.</p>	

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10	Responsibilities	The researcher	<ul style="list-style-type: none"> <li>The researcher has been advised about the role of a researcher.</li> <li>Ethical approval has been sought, as well as a full risk assessment being completed.</li> <li>Understanding of ethics, safeguarding and other responsibilities which may arise during data collection have been discussed, and supporting reference provided (as appropriate).</li> </ul>	a. Low – the risk of harm is low as the researcher has a good understanding of possible challenges, as well as their role within the data collection process.	
11	Dress and familiarity	The researcher	<ul style="list-style-type: none"> <li>A professional manor will be adopted in all phone and written communications.</li> <li>A professional email address and phone number will be provided.</li> <li>A professional but relaxed image will be adopted in the researchers dress code during the online workshops, with the web cam being on throughout the duration of the 'live' times.</li> </ul>	<p>a. Low – the risk of harm is low as the researcher has created drafts for recruitment material and other standard messages which may be required during data collection.</p> <p>b. Contact details for project supervisors and the head of school are provided should any concerns about how the research was conducted arise.</p>	
12	Personal samples	The research	<ul style="list-style-type: none"> <li>Recordings will be stored on a password protected and encrypted device only accessible by the research team.</li> <li>Confidentiality will be discussed during the participant workshops.</li> </ul>	a. Low – all relevant controls have been put into place to ensure the risk of samples being identified, or shared incorrectly, thus causing harm, are very low.	

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			<ul style="list-style-type: none"> <li>Individuals names and any identifiable material will be removed from the data.</li> </ul>	b. The study was granted ethical approval, and data will be stored in accordance to GDPR and University Governance.	
13	Tools needed e.g., laptop, digital recorder.	Materials and equipment	<ul style="list-style-type: none"> <li>All forms of written communication between the researcher, research team, and participants will be through a password protected account.</li> <li>Tools used to store data, namely the audio recording device, will be encrypted and password protected.</li> <li>Participants will be aware that they are being recorded, as well as this being explained on the information sheets. This is also a specific point on the consent form.</li> </ul>	<p>a. Low – several controls have been put in place to ensure that confidentiality is upheld.</p> <p>b. The researcher has experiences using the specific equipment, such as the audio recording feature within teams.</p> <p>c. Power supplies will be established with the setting prior to data collection, as well as a reserve method should the primary method not be viable. In addition, a quiet space where the researcher will not be disturbed has been identified.</p>	
14	Location	The location	<ul style="list-style-type: none"> <li>Lone working policy will be considered, as well as supervisors being aware of where and when data collection is taking place.</li> <li>Another individual will be present through live discussions, they will not participate but act as a moderator.</li> </ul>	a. Low – relevant controls have been put into place.	
15	Will the location be accessible by other people	The location	<ul style="list-style-type: none"> <li>The sites may be accessible by others when completing live discussions, however, guidance will</li> </ul>	a. Low – measures have been put into place to ensure participants are safe.	

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			<p>be given about the need for a quiet space and using headphones. Participants will also be advised that their screen should not be visible during participation.</p> <ul style="list-style-type: none"> <li>• Reminding participants using web-cam to not have in sight anything which may identify their location or their identity (advise blank background and no identifiable personal affects).</li> <li>• A sign will be put on the door (if within a University premises) and any entrances to the room where data collection is taking place (researcher).</li> </ul>		
16	Duty of care	Emergency arrangements	<ul style="list-style-type: none"> <li>• Research supervisors will be aware of when and where data collection is taking place and will be available should the researcher have any concerns.</li> <li>• The researcher will also have contact information of support should an emergency arise, or a disclosure which warrants breach of confidentiality be made.</li> <li>• Debriefing will take part after participants have completed the</li> </ul>	<p>a. Low – the researcher is aware of relevant requirements and legislation, as well as having contact with advisors should an emergency arise.</p> <p>b. A full DBS check has been obtained, as well as ethical approval about the way in which the study is being conducted.</p>	

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			<p>stages of the study. They will be given the opportunity to ask questions and be provided a summary for their information.</p> <ul style="list-style-type: none"> <li>The researcher is aware of confidentiality and safeguarding, and occurrences when this may be breached (namely if the individual was presenting as a risk of harm to themselves or others).</li> </ul>		