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Investigating Parents' Etiological Beliefs and Assessment Experiences when a Diagnosis is not given

Bendik, Lesley-Anne

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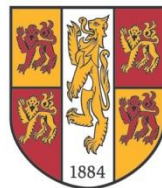
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**Autism: Investigating Parents' Etiological Beliefs and Assessment Experiences when a  
Diagnosis is not given.**

Lesley-Anne Bendik

North Wales Clinical Psychology Programme

Bangor University



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Submitted in part fulfillment for the degree of Doctorate in Clinical Psychology

June 2017

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Secondly, to my research supervisor, Dr. Freya Spicer-White. Your passion and determination for working with families and young people with autism and improving autism services is a true inspiration. Thank you for your encouragement and calming influence over the past two years. I would also like to extend this gratitude to the wonderful Neurodevelopmental team, whose constant hard work, humor and three o'clock brews were invaluable.

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## **Thesis Abstract**

This thesis explores different aspects of parents' perceptions of Autism Spectrum Disorder (ASD) across three individual papers.

The first paper presents a systematic review focusing on parents' beliefs about the cause and course of their child's autism. The review synthesises the results of fifteen studies which met the inclusion criteria to update the findings of a previous review. Parents held a range of etiological beliefs, although genetics/heritability, pre and post natal exposure, brain abnormalities and religious beliefs were the most common. Culture and socio-demographic variables were associated with parents' beliefs and influenced their perceptions about the course of ASD along with a number of personal and healthcare decisions. Methodological constraints and variation in reporting results presented difficulties in comparing these findings to the previous research and providing an accurate conclusion regarding the most widely accepted belief. Areas for future research are highlighted along with clinical recommendations for improved parent-professional communication and the provision of evidence-based information to facilitate informed decision-making.

The second paper presents the results from an empirical study which looked at parents' lived experience of the ASD assessment process when a diagnosis was not given. Parents' views in this context have previously been underrepresented. In total six interviews were conducted and parents' experiences were explored using interpretative phenomenological analysis. Three superordinate themes transpired which illustrated the issues that parents encountered in recognising, disclosing and celebrating their child's differences, the emotional and psychological impact of the assessment, along with difficulties in understanding the outcome. Research limitations and clinical implications are discussed.

The final paper considers the clinical and theoretical implications arising from both papers. Recommendations for best practice include more professional training, pre and post

assessment counselling, needs-led service provision, policy development and ongoing audit and evaluation. A personal reflection of the research process is provided.



**Parental Beliefs about the Cause of Autism Spectrum Disorder:  
An Updated Review of the Literature.**

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## RESEARCH IN AUTISM SPECTRUM DISORDERS

### AUTHOR INFORMATION PACK

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#### DESCRIPTION

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[dataset] Oguro, M., Imahiro, S., Saito, S., Nakashizuka, T. (2015). Mortality data for Japanese oak wilt disease and surrounding forest compositions. Mendeley Data, v1. <http://dx.doi.org/10.17632/xwj98nb39r.1>. Examples Reference to a journal publication:

Van der Geer, J., Hanraads, J. A. J., & Lupton, R. A. (2010). The art of writing a scientific article. *Journal of Scientific Communications*, 163, 51-59.

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## **Abstract**

*Background:* Despite extensive research investigating the etiological factors associated with autism spectrum disorder (ASD) the outcome remains unclear. Without clear guidance from scientists or professionals, parents are left to construct their own interpretation of the disorder. This area has been largely neglected in the research, although a previous review (Hebert & Koulouglioti, 2010) identified that parents hold a range of etiological beliefs and that these beliefs can have serious implications for both the parent and child. The aim of this paper was to provide a comprehensive and updated review of the literature regarding parents' beliefs about the cause and course of autism, factors associated with these beliefs and their implications.

*Methods:* Electronic databases, Ovid (including Medline, Embase and PsychINFO) and CINAHL were searched systematically for articles published between 2009-2017. Fifteen studies which met the inclusion criteria were identified.

*Results:* Parents believed a wide range of factors were responsible for causing their child's autism, but most frequently endorsed genetics/heritability, pre and postnatal exposure, brain abnormalities and religious causes. In many cases, beliefs were associated with culture and socio-demographic variables. Healthcare, treatment and family planning decisions were influenced by parents' etiological beliefs, along with their communication with clinicians, their own well-being and perceptions about their child.

*Conclusions:* Given the range and impact of parents' causal beliefs about their child's autism, clinicians should openly discuss this with parents during the assessment. In addition, evidence-based information should be provided to facilitate informed decision-making. Limitations, clinical implications and recommendations for future research are discussed.

**Keywords:** autism; parents; beliefs; culture; systematic review.

## 1.0 Introduction

Autism Spectrum Disorder (ASD) is a complex, lifelong neurodevelopmental disorder, affecting approximately 700,000 individuals in the United Kingdom and 1% of the population worldwide (Centres for Disease Control and Prevention [CDC], 2014). There is no specific test for autism and diagnosis is made in accordance with an observable set of behaviours or the absence of age-appropriate social interaction, communication and imaginative play skills (*Diagnostic & Statistical Manual of Mental Disorders*, 5<sup>th</sup> ed.; DSM-5; American Psychiatric Association [APA], 2013).

To date, there is no conclusive evidence regarding the precise etiological factors which predispose someone to ASD (Huguet, Ey & Bourgeron, 2013). However, the pursuit to expose and understand these factors is an area of increasing interest due to the recent rise in prevalence rates (Matson & Kozlowski, 2011). Since the earliest identification of autism, theories regarding its etiology have oscillated between explanations of nature and nurture. Original theories were influenced by psychogenic perspectives, which predominantly blamed parents, particularly mothers, for their child's atypical behaviours (Kanner, 1943). As such, inadequate attachments between the mother and child or early childhood trauma were implicated as the primary cause (Bettelheim, 1967). However, these theories were strongly refuted by parents with the support of Rutter (1968), who introduced the idea that abnormalities within the child's neurological development was a more credible explanation. This prompted a greater focus on biomedical explanations, which are now widely accepted due to extensive research using behavioural genetic analysis, including twin and family studies (Tick, Bolton, Happé, Rutter & Rijdsdijk, 2016). Nevertheless, whilst the research suggests that autism has a substantial genetic foundation with strong heritability, the exact genomic architecture remains unknown (NICE, 2011). Consequently, the role of environmental influences as either the sole cause, or as a risk factor, which may trigger the development of autism for individuals with a genetic

predisposition have been considered (Grabrucker, 2013). Within this literature, pre, peri and postnatal factors are considered and include; advanced parental age, maternal diabetes, prematurity and hypoxia (Kolevzon, Gross & Reichenberg, 2007; Krakowiak et al., 2012); drug use during pregnancy (Boukhris, Sheehy, Mottron & Bérard, 2016); maternal infection (Zerbo et al., 2015) and toxin exposure (Kalkbrenner, Schmidt & Penlesky, 2014). In most cases, however, the evidence remains inconclusive. In the case of toxin exposure, specifically the association between the measles, mumps and rubella (MMR) vaccine and autism (Wakefield et al., 1998), the research has been discredited (Flaherty, 2011). Despite inconsistent findings, there is a growing appreciation that autism could be caused by the complex interplay between genetic and environmental factors (Matelski & Van de Water, 2016; Sandin et al., 2014).

Current research is dominated by academic and scientific explanations and little is known about parents' etiological beliefs. "Beliefs are the lenses through which we view the world" (Wright, Watson & Bell, 1996, p.67). They are constructed and shaped through cultural and societal values, personal experiences, attitudes, interactions with professionals and are susceptible to change; particularly in response to life changing events, such as parenting a child with autism (King et al., 2006). When a child is diagnosed with an illness or disability, parents often search for explanations regarding the cause, course and treatment options (Morgan & Tan, 2011). During this search process, parents create "Explanatory Models" (EMs), which are frameworks used to comprehend and navigate the child's difficulties (Kleinman, 1980).

Given the absence of a definitive causal explanation and treatment advice, despite extensive research on etiological factors and behavioural, educational and alternative therapies, parents are consequently left to construct their own interpretations of ASD (Gona et al., 2015). Personal and cultural beliefs, social class, spirituality and education influence the development of an individual's EM (Pachter, 1994). This implies that EMs are likely to vary significantly

between individuals and most recognisably across different cultural backgrounds. Several studies have examined the development and impact of parents' EMs in relation to help-seeking behaviours. Their findings demonstrate that parents' and professionals' explanations frequently differed regardless of whether the child had ASD (Gray, 1995), Attention Deficit Hyperactivity Disorder (Klasen & Goodman, 2000) or asthma (Bokhour et al., 2008). Exploring parents' beliefs is clinically important to determine the influence of such beliefs on treatment decisions, the parent-child relationship and their own psychological acceptance of the diagnosis.

Hebert and Koulouglioti (2010) attempted to address this research gap. In a review of twelve studies they found that parents held a number of causal factors accountable for their child's ASD. These included, genetics, environmental factors and complications during birth through to early childhood. Despite retraction of the vaccine-autism link, many parents still believed this to be a causal factor, although later studies suggested the prevalence of this was decreasing. The impact of parents' causal beliefs affected three areas; 1) maternal mental health; 2) healthcare decisions; and 3) family planning. Whilst these findings offer a useful insight to parents' beliefs prior to 2009, more research was recommended. In line with other disabilities, Hebert and Koulouglioti (2010) suggested additional research was needed to determine the impact of culture on parents' etiological beliefs and to determine the relationship between beliefs and treatment selection.

For professionals to support parents effectively, understanding their perceptions about autism is invaluable. In view of the evolving beliefs suspected in the previous review, the present aim was to provide an updated review of the literature and improve knowledge in this area. In accordance with the previous review, and to compensate for diagnostic changes in the DSM-5 during the time frame of reviewed studies (2009-2017) all forms of ASD including classic or high functioning autism, Asperger syndrome and Pervasive Developmental Disorder



– Not Otherwise Specified (PDD-NOS) will be considered and referred to as autism or ASD (APA, 2000, 2013).

## **1.1 Aims**

The current review aimed to explore the following questions:

1. What causal beliefs do parents hold about their child's ASD?
2. What do parents perceive about the course of ASD?
3. What are the implications of these perceptions?

## **2.0 Method**

### **2.1 Search Strategy**

A systematic search was performed in February 2017 using the following electronic databases; Ovid (including Medline, Embase and PsychINFO) and CINAHL. The following terms were adopted to search abstracts and titles: '*autism spectrum disorder*', '*autistic disorder*', '*parents*', '*beliefs*', '*perceptions*', '*cause*', '*etiology*', '*aetiology*', '*culture*' and their associated deviations (e.g. *autis\**, *caus\**, *parent\** and *cultur\**). In all databases language and date parameters were restricted to studies published in English between 2009 and 2017. For the three databases searched via Ovid an additional parameter was set to remove duplicates.

### **2.2 Inclusion Criteria**

Studies were included if they met the following criteria:

- Published between 1<sup>st</sup> January 2009 and 28<sup>th</sup> February 2017.
- Published in English.
- Published in a peer-reviewed journal.
- Findings reported parents' beliefs about the cause or course of ASD.

### **2.3 Quality Assessment**

A review of quality assessment tools asserted that whilst there are many effective tools for clinical trial research, tools for assessing other methodologies including observational epidemiological research are inadequate (Sanderson, Tatt & Higgins, 2007). Given the nature of this research, clinical trials were not applicable in the selected studies and therefore quality was appraised by the authors, rather than a formal assessment tool.

### **2.4 Study Selection Process**

Selection was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff & Altman, 2009). The initial search returned 1466 records, of which 183 duplicates were removed by EndNote<sup>TM</sup> (a reference management software) and by hand. A further 1195 articles were excluded subsequent to screening abstracts in accordance with the inclusion criteria. In total, 88 articles were read in full and 16 met criteria. One paper (Selkirk, Veach, Lian, Schimmenti & LeRoy, 2009) was included in the previous review (Hebert & Koulouglioti, 2010) and was therefore discarded, leaving a total of 15 articles. A hand search of all reference lists for further studies was performed, but none were found. Figure 1. Illustrates the selection process and reasons for exclusion.

[INSERT FIGURE 1]

### **2.5 Data Extraction**

The final articles (n=15) were analysed by the first author and data was extracted systemically. Extracted data included; 1) author and year of publication; 2) research location; 3) sample size and response rate; 4) recruitment method; 5) parent characteristics; 6) child characteristics; and

7) method of data collection (Table 1). A summary of the findings was also extracted and included, 1) research focus; 2) measurement method; 3) parents' beliefs about the cause or course of autism); 4) implications; and 5) limitations (Table 2).

## **2.6 Data Synthesis**

Due to the heterogeneity of the final studies regarding research design, sampling methods and outcomes, this review will be presented as a narrative synthesis as opposed to a meta-analysis. This was considered the most appropriate method to summarise and explore the qualitative and quantitative findings presented in each study (Hong, Pluye, Bujold & Wassef, 2017).

## **3.0 Results**

### **3.1 Descriptive Overview**

#### *Sample Characteristics*

Of the 15 studies reviewed, seven were conducted in the United States (Bazzano, Zeldin, Schuster, Barrett & Lehrer, 2012; Fischbach, Harris, Ballan, Fischbach & Link, 2016; Goin-Kochel, Mire & Dempsey, 2015; Jegatheesan, Miller & Fowler, 2010; Wasserman, Weisman de Mamani & Mundy, 2010; Zuckerman, Lindley, Sinche & Nicolaidis, 2015; Zuckerman, Lindley & Sinche, 2016). Two were conducted in Taiwan (Chen et al., 2015; Shyu, Tsai & Tsai, 2010) and one each in France (Dardennes et al., 2011), Turkey (Bilgic et al., 2012), Saudi Arabia (Alqahtani, 2012), Jordan (Al Dababneh, Al-Zboon & Baibers, 2016) and the Kenyan Coast (Gona et al., 2015). The final study was an internet survey completed in multiple locations, including Canada, USA and Kuwait (Ravindran & Myers, 2012).

Collectively, the findings report on 2,645 parents of children with ASD. This was based on 14 studies, given that two studies used the same sample to examine different outcomes (Zuckerman et al., 2015, 2016). The sample sizes varied significantly from six participants

(Jegatheesan et al., 2010) to 1420 participants (Zuckerman et al., 2015, 2016). Three studies compared parental beliefs to the beliefs of others, including professionals (Gona et al., 2015; Fischbach et al., 2016) and parents of children with schizophrenia (Wasserman et al., 2010). The comparative participants were not included in the sample characteristics. Of the eight studies who reported participants' parental role, 633 were mothers whilst 86 were fathers, their age ranged from 27-75 years. Ten studies reported demographic information for the children, revealing that 1645 were boys and 389 were girls, who ranged from 2-44 years in age. The inclusion of more boys than girls reflects current prevalence rates (Lai et al., 2015).

Whilst all studies included parents of children with ASD, seven classified diagnosis subtype, four classified severities, and although five classified diagnosis age, only one reported the time frame between the diagnosis and the research (Bilgic et al., 2012). Diagnostic information was corroborated in eleven studies using parental self-report (Ravindran & Myers, 2012; Zuckerman et al., 2015, 2016), researcher validation (Alqahtani 2012; Bazzano et al., 2012; Gona et al., 2015; Fischbach et al., 2016; Wasserman et al., 2010), independent clinicians (Bilgic et al., 2012; Shyu et al., 2010) or DSM-IV screening (Dardennes et al., 2011).

Most studies reported socio-demographic information including the participants' religious or ethnic status (n=12), parents' education status (n=11) and household income (n=8). However, reporting varied significantly across the studies (Table 1) and thus will be discussed in more detail as appropriate to individual findings.

### *Method and Design*

There were seven qualitative studies. Of these, five used face-to-face semi-structured interviews (Alqahtani, 2012; Al-Dababneh et al, 2016; Chen et al., 2015; Shyu et al., 2010), one of which also incorporated focus-groups (Gona et al., 2015). One used an online or telephone semi-structured questionnaire (Ravindran & Myers, 2012) and one combined face-

to-face and telephone interviewing (Jegatheesan et al., 2010). Six studies were quantitative, five included interviewer-administered questionnaires either in person (Bilgic et al., 2012; Zuckerman et al., 2015, 2016) or via telephone (Bazzano et al., 2012; Fischbach et al., 2016) and one mailed questionnaires (Dardennes et al., 2011). The two remaining studies used mixed methodology. Goin-Kochel et al., (2015) used mailed questionnaires to determine parents' agreement with a list of causal beliefs, followed by an open-ended question. Wasserman et al., (2010) provided an interviewer-administered questionnaire to assess causal beliefs, followed by a five-minute speech sample to determine attributions parents make about their child. All studies were cross-sectional except for Jegatheesan et al., (2010), which involved 17 months of ethnographic fieldwork, interviewing families in their home and community.

Regarding recruitment, three studies advertised through autism-related groups or websites, six recruited via education or medical settings, one of which (Jegatheesan et al., 2010) also recruited using participants' contacts. The remaining six studies re-contacted parents subsequent to previous participation in research.

### *Outcome Measures*

Five of the quantitative studies utilised widely recognised questionnaires to ascertain parents' etiological beliefs. The most common being the Illness Perception Questionnaire, revised for Autism (IPQ-R), a validated measure for assessing health beliefs in parents of children with ASD (Al Anbar, Dardennes, Prado-Netto, Kaye & Contejean, 2010). This revised questionnaire used by Goin-Kochel et al., (2015) and Zuckerman et al., (2015, 2016) utilised adapted wording to facilitate caregiver responses alongside the addition of autism-related symptoms and potential causes. Although the sample in Zuckerman et al., (2015, 2016) were all parents of children with ASD, they were recruited from a larger study where children could have additional diagnoses. Correspondingly they further adapted the wording to enquire about

causes of the child's "learning and developmental conditions" rather than "autism" per se and thus results are considered with caution. Dardennes et al., (2011) used the Lay-Beliefs about Autism Questionnaire (LBA-Q; Furnham & Buck, 2003). This explores etiological beliefs based on parents' responses to a 7-point Likert scale which indicates their agreement with 24 causal statements. Wasserman et al., (2010) used a variation of the Causal Dimension Scale (CDS; Russell, 1982) to determine parents' attributions about symptoms and causes of ASD in a comparative study between parents of adult children with autism or schizophrenia. All other studies created their own questions to assess outcomes.

[INSERT TABLE 1]

### **3.2 Parents' beliefs about the causes of ASD**

Fourteen studies examined parents' causal beliefs regarding their child's ASD (Table 2).

#### *3.2.1 Quantitative Findings*

Six studies used quantitative analysis. Amongst these, four studies reported that parents predominantly believed that genetic/hereditary factors caused their child's autism. Studies which asked participants to rate their agreement with a list of factors, found that agreement with genetics/heritability ranged from 66.3% (Zuckerman et al., 2016) to 75.8% (Goin-Kochel et al., 2015) of the total sample. Notably, Zuckerman et al., (2016) found that socio-demographic variables were associated with these beliefs. Biological parents, parents of Hispanic children and children without private health insurance were less likely to "definitely" agree on genetics/heritability as a cause compared to non-biological parents or parents of Caucasian or privately insured children. Studies which calculated responses from open-ended questions found that genetics/heritability was cited by between 43% (Bilgic et al., 2012) and

55% (Fischbach et al., 2015) of samples. The later study also provided a comparison to scientists' beliefs ( $n=60$ ), of which a much higher percentage (95%) agreed with genetics/heritability as the primary cause.

Another commonly cited factor was pre and post-natal toxin exposure. Two studies listed exposure as one potential cause. Zuckerman et al., (2016) reported that 35.4% and 41% "somewhat/definitely" agreed with pre and post-natal exposure causes, respectively. They further specified that parents of black children and those with low incomes were more likely to "definitely" agree with post-natal exposure as the cause of their child's ASD. Parents whose children showed functional limitations were also more likely to endorse post-natal causes compared to those without. Similarly, Goin-Kochel et al., (2015) reported that 41.7% agreed toxins in vaccines were to blame whilst 37.3% believed ASD resulted from exposure to environmental pollution. This study examined whether ASD-onset type (early onset, plateau, delay + regression or pure regression) was associated with causal beliefs. Whilst no significant differences were detected initially due to the small sample size and low power to detect between-group differences the authors combined the categories (regression / no regression) and repeated the analysis to determine whether witnessing regression influences beliefs. Repeated analysis revealed a significant difference between groups regarding their belief that toxins in vaccines cause ASD,  $F(1,66) = 3.74$ ;  $p < 0.05$ . Parents who witnessed their child regress had stronger beliefs in vaccines as a cause ( $M = 2.4$ ,  $SD = 1.2$ ) compared to those whose children demonstrated early symptom onset and thus did not regress ( $M = 1.8$ ,  $SD = 1.3$ ). A trend [approaching significance,  $F(1,66) = 3.25$ ,  $p = 0.07$ ] was also revealed showing that parents whose child regressed held stronger beliefs in environment pollution as a cause ( $M = 2.3$ ,  $SD = 1.0$ ) compared to those whose children had early-onset ASD ( $M = 1.7$ ,  $SD = 1.4$ ).

Two studies analysed freely cited responses. In Bilgic et al., (2012) which was conducted in Turkey, 16% endorsed vaccines as the cause of ASD whilst 14% specified it was

due to the toxicity of mercury. However, this was much lower than other factors within their sample, which included birth complications (46%), genetics (43%) and poor parenting (20%). Fischbach et al., (2016) which is the most recent study and conducted in the USA found that parents' agreement with vaccines was lower as only 13% cited "vaccines" and 9% cited "environmental exposure".

Vaccines as a causal belief was the primary focus in Bazzano et al., (2012). They surveyed a large sample (n=460) to assess whether parents did or did not attribute ASD to vaccines. A relatively even split was found as 32% of parents believed vaccines was the cause and 17% assumed they possibly contributed, whilst 34% believed vaccines were not responsible and 17% were unsure. Factors including the child being vaccinated prior to diagnosis, higher parental education and parents' ethnicity being Latino or African American as opposed to Caucasian, were associated with a stronger belief that vaccines caused ASD. The high number of parents (n=225) who endorsed vaccines as a causal factor, despite the retraction of the vaccine-autism link (Wakefield et al., 1998), potentially highlights the long-term media influence along with communication deficits between parents and professionals. Conversely, in a French study Dardennes et al., (2011) found that from 88% of 78 parents who spontaneously cited causal beliefs, only six cited vaccines and only three cited vaccines as the primary cause. Unfortunately, it is not possible to determine whether the rates of parents endorsing such beliefs are reducing as suggested in the previous review (Hebert & Koulouglioti, 2010) as the extent to which parents agreed with this factor was unreported.

Brain abnormality, development and structure were also most commonly cited. Agreement was reported by 59.7% in Goin-Kochel et al., (2010) and was the strongest belief (m=6.04) as rated on a 7-point Likert scale in a study which asked parents to rate their agreement with 12 causal factors (Dardennes et al., 2011).



Other factors commonly reported, albeit only by a small percentage of each sample, included; diet (Bilgic et al., 2012; Fischbach et al., 2016); prematurity or birth complications (Bilgic et al., 2012); and childhood accident, injury or illness (Zuckerman et al., 2016). The later study found that parents with low income were more likely to endorse accident, illness or injury causes. Only two quantitative studies reported beliefs associated with religious factors such as ‘destiny’ reported by 4% in Bilgic et al., (2012) and belief in ‘God’s will’ reported by 46.3% in Goin-Kochel et al., (2015), who also found that 90% of parents believed in two or more factors.

Some studies reported that participants did not know what the cause was, a finding which ranged from 7% (Fischbach et al., 2016) to 30.6% (Zuckerman et al., 2016). This reflects the uncertainty of scientists but also highlights the potential confusion facing families.

### *3.2.2 Qualitative Findings*

Some qualitative studies presented results as themes with illustrative quotes whilst others used content analysis and presented findings as percentages. In comparison to the quantitative studies more variation was reported. However, genetic/heritability was still one of the most common beliefs. Chen et al., (2015) specifically examined 39 Taiwanese parents’ perceptions about genetics as a cause of ASD, and separately as a cause of their child’s ASD. Whilst the majority of parents (74%) agreed that genetics cause ASD, less than half (43%) agreed it caused their child’s ASD. The authors attributed this finding to the Theory of Cognitive Dissonance (Festinger, 1962), stating that parents show preference for non genetic/hereditary causes as a coping mechanism. It absolves them of responsibility for their child’s condition and helps them to avoid stigma and community isolation, which are often experienced by families raising children with genetic conditions in Asian cultures. Shyu et al., (2010) also studied Taiwanese parents. They used a grounded theory approach and unlike Chen et al., (2015) found that all

participants endorsed biological factors (albeit including genetics and brain abnormalities). However, most parents endorsed more than one causal factor, which predominantly included nutrition deficiency and supernatural causes.

Other studies reporting genetics as the most popular belief include Goin-Kochel et al., (2015). They found that when asked to write their top three causal beliefs, 42.6% of parents stated genetics, followed by 22.1% who stated environmental factors (of note, 76.6% of those parents specified vaccines). The majority of participants in Wasserman et al., (2010) also reported genetics alone or combined with environmental factors. Similarly, when the 22 participants in Ravindran and Myers (2012) were asked to spontaneously cite their beliefs, most (38%) reported genetic or environmental causes, followed by parents who did not know (30%) and parents who stated vaccines (25%). This study specifically looked at the impact of culture on parents' beliefs, by assessing parents who had relocated from India to live in Western cultures. They found that when asked to rate agreement with a list of causal factors, parents' had stronger beliefs in factors typically associated with Western culture (environmental toxins, genetics and vaccines) compared to those associated with traditional Indian culture (destiny, karma and punishment for parental mistakes in a past-life). However, a high proportion of parents drew beliefs and practices from both cultures without conflict.

Of the remaining studies, three (Alqahtani et al., 2012; Al-Dababneh et al., 2016; Gona et al., 2015) reported mixed findings between biomedical factors (e.g. genetics, medical investigations during pregnancy, parental age, birth complication) and preternatural causes (e.g. a gift from God, a curse, witchcraft, evil eye, black magic). However, Alqahtani (2012) found that beliefs altered dependent upon treatment success. For example, some parents initially reported beliefs associated with medical explanations, yet retracted this if medical interventions failed to demonstrate improvement. The final study (Jegatheesan et al., 2010) reported that all parents' believed ASD was a gift from Allah.

### **3.3 Parents perceptions about the course of ASD**

Five studies reported relevant findings, which appeared somewhat related to parents' causal beliefs. Parents from the Kenyan Coast who perceived ASD to be a bad omen caused by preternatural factors, were hopeful that treatment was curative (Gona et al., 2015). Alternatively, American parents who perceived ASD as a gift held positive expectations about the child's future (Jeagatheesan et al., 2010).

The previous review considered the concept of vicarious futurity, described as “the hope and despair one has for another's future” (Hebert & Koulouglioti, 2010, p. 157). Similar findings were presented in Al-Dababneh et al., (2016). Parents were optimistic about their child's future, but were either doubtful that they would achieve a satisfactory level or highlighted the time and patience this would require. Some parents cited particular worries about their child's future, including their societal role, inheritance rights and rights to vote (Shyu et al., 2010). These worries are likely to be influenced by societal expectations and their lack of acceptance around disability.

Zuckerman et al., (2015) found that socio-demographic variables influenced parents' ASD-related expectations, because whilst 70.8% “definitely” believed ASD was lifelong, this was predominantly reported by parents of Caucasian compared to Hispanic children.

### **3.3 Implications of parents' beliefs**

#### *3.3.1 Treatment selection and parent-professional relationships*

Six studies found associations between causal beliefs and treatment selection. Gona et al., (2015) found cultural beliefs to be influential in treatment decision-making, as those who endorsed supernatural beliefs consulted with fortune-tellers or traditional healers rather than

medical professionals. In a Taiwanese study, Shyu et al., (2010) also found that parents' EMs affected therapy decisions and that parents could combine multiple beliefs (biomedical and supernatural beliefs) without apparent conflict. Correspondingly, this was reflected in their decision to consult both fortune-tellers and medical professionals simultaneously. Similarly, in Alqahtani (2012) where parents from Saudi Arabia largely believed in cultural causes or medical investigations during pregnancy, all parents reported using cultural-based treatments (e.g. reading the "Al-Quran" or liaising with religious healers), with the exception of special diets or hyperbaric oxygen therapy. Whilst etiological beliefs were thought to be related to treatment choice, over half of the sample used special diets, despite complete absence of food-related factors as a perceived cause.

Nevertheless, two studies reported more specific associations. Dardennes et al., (2011) found that etiological beliefs of early trauma were associated with less use of behaviour therapies and communication aids; illness beliefs were associated with increased medication use; and beliefs about food allergies were positively associated with detoxification and special diets. Bilgic et al., (2012) who examined parents' beliefs and complementary and alternative medicine (CAM) use, reported no association with socio-demographic or diagnostic factors. However, they did find that parents who endorsed genetic beliefs were less likely to use CAM ( $X^2=7.1$ ,  $p=0.008$ ) and those who endorsed vaccine beliefs were more likely to use CAM ( $X^2=4.8$ ,  $p=0.03$ ). They further reported that whilst over half of their sample (56%) used CAM, only 23% disclosed this to the child's clinician.

In addition to treatment selection, etiological beliefs impact on parent-therapist relationships. Jegatheesan et al., (2010) found that parents who perceived ASD as a gift, objected to clinicians focusing on the child's difficulties rather than their accomplishments. Consequently, this caused conflict regarding treatment options. Parents opted for full inclusion

of the child into their multilingual community, whereas professionals advocated for basic, segregated, monolingual teaching opportunities.

### *3.3.2 Vaccine Schedules*

The previous review highlighted that parents who suspected that vaccines caused their child's ASD frequently altered their vaccination schedule (Hebert & Koulouglioti, 2010). Consistent results were reported by Bazzano et al., (2012). They found that whilst 48% of parents “definitely” or “possibly” believed vaccines were the cause, 35% varied how vaccines were administered and 21% discontinued vaccines altogether. Although beliefs in vaccines were associated with Latino and African American parents, altered vaccine decisions were more strongly associated with Caucasian parents. No association was found between altered decisions and parents' education or insurance status. The most recent study, Fischbach et al., (2016), highlights that the issue of vaccine decisions is ongoing for many parents. They found that despite only 13% of their sample (n=502) believing in vaccines as the cause, 37% would hesitate getting their child vaccinated.

### *3.3.3 Perception of child*

The comparative study by Wasserman et al., (2010) found that parents of children with autism were less critical and made fewer blameworthy attributions about their child than parents of children with schizophrenia. The authors postulated that the early onset of autism, compared to schizophrenia, and the stronger causal beliefs in genetics from parents of children with autism contributed to their perception that the diagnosis was beyond the individuals' control. Although these findings are based on different diagnoses, they offer insight into children whose autism is diagnosed later, or for parents who believe in non-biological causes.

### *3.3.4 Family Planning*

Chen et al., (2015) evaluated the impact of causal beliefs in relation to family planning. They found that 38.5% of parents reported high recurrence risk, whom had all decided against further children or would terminate future pregnancies. Interestingly, only one parent based their recurrence risk on medical advice, whilst others drew on assumptions about family histories, intuition or their own research. However, the authors reported parents' perceived recurrence risk was inaccurately high.

### *3.3.5 Maternal Impact*

In two studies, conducted in Saudi Arabia and Jordan, mothers expressed guilt for potentially causing their child's diagnosis (Alqahtani, 2012; Al-Dababneh et al., 2016). The second study found that this was due to their perceived carelessness or psychological stress during pregnancy, although the authors argued that this perception was also likely to be instilled by community attitudes.

[INSERT TABLE 2]

## **4.0 Discussion**

The current review aimed to explore parents' beliefs about the cause and course of their child's autism to update the literature. The findings will be discussed and subsequently compared to the previous review.

Parents held a range of beliefs, which predominantly included: genetic/hereditary factors, pre and postnatal exposure including vaccinations, abnormal brain structure and religious beliefs. Whilst little is known about why parents' perceptions are held, some studies reported associated factors, including culture and socio-demographic variables. One study

which examined the impact of culture and the effect of acculturation found that parents drew from both their traditional (Indian) and current (Western) cultural environments, but the extent of this varied between families (Ravindran & Myers, 2012). This suggests that culture is not only a strong influential factor in the formation of beliefs, but that parents' beliefs are fluid and adapt accordingly. This highlights the importance of clinicians becoming more culturally aware and developing cross-cultural competencies.

Another variable implicated in the formation of beliefs and expectations related to the child's developmental trajectory in terms of symptom onset and time of diagnosis. As found in the previous review, regressive symptom-onset was associated with beliefs in external factors such as vaccines or environmental pollution (Goin-Kochel et al., 2015). Whereas the early diagnosis of autism, compared to other conditions such as schizophrenia, caused parents to perceive the disorder as being beyond the individuals' control. Consequently, this had positive implications for parents' perceptions of their child (Wasserman et al., 2010).

The gap in scientific knowledge regarding the exact cause or best treatment options for autism, leads parents to develop their own beliefs. Whilst some parents reported that they did not know what to believe, others held multiple etiological beliefs, which were found to coexist without conflict (Shyu et al., 2010). Alternatively, some parents were more confident to report factors they did not believe in compared to those in which they did (Goin-Kochel et al., 2015). Although, understanding the beliefs of others was not central to this review, one study which drew comparisons revealed significant discordance between the beliefs of parents and scientists (Fischbach et al., 2016).

Understanding parents' etiological beliefs, offered a number of important insights into the parent-child relationship, their goals and aspirations for the child, service utilisation and preferred treatment approaches. Treatment selection in particular appeared to have strong associations with the parents' beliefs. Those who held religious etiological beliefs were more

likely to consult non-medical treatments (Gona et al., 2015) compared to a belief in illness causes (Dardennes et al., 2012). Other treatment decisions were associated with vaccine schedules (Bazzano et al., 2012). A large number of parents reported to alter or discontinue their child's vaccination schedule, despite the potential for serious consequences. Therefore, healthcare providers need to ensure they communicate openly and provide sufficient information to ensure parents make well-informed decisions for their child with ASD and their siblings. Again this was consistent with results from the previous review, and thus highlights that despite the MMR vaccine-autism link being discredited a number of years ago, the attention this received in the media at the time continues to have a lasting impact. One study also reported that due to the unknown etiological factors, parents were willing to try any treatment (Shyu et al., 2010). Without guidance from healthcare providers the implications could be serious, and to some extent are already a concern given the high number of parents using CAM therapies, many of which are costly to families and are not scientifically-validated (Bilgic et al., 2012). A recent review on CAM use, by Jobski, Höfer, Hoffmann and Bachmann (2016) recommended that clinicians should be aware of CAM therapies and specifically enquire about this with families.

The outcome of beliefs can have additional implications for the parent. In line with the attribution theory (Weiner, 1985), the attributions people make about a given event can also impact on their own well-being and coping ability. Parents who attributed etiological beliefs to internal causal attributions, such as hereditary factors or their own carelessness during pregnancy felt guilty and responsible for their child's difficulties (Alqahtani, 2012). In previous research, similar findings have further reported that such attributions impact on the parents' level of involvement with the child (Dale, Jahoda & Knott, 2006).

Another parent outcome related to family planning decisions. Many parents reported that having one child with ASD negatively influenced their decision for more children.



However, Chen et al., (2015) found that parents' perceived recurrence risk was often inaccurately high and based on unscientific sources of information. Therefore, clinical awareness of such issues is important. Services need to ensure families are provided with evidence-based information, the opportunity to discuss concerns and where appropriate are referred for genetic counselling to support well-informed reproductive decisions.

Whilst there are a number of findings related to outcomes of parents' beliefs, information regarding their views about the course of autism was limited. Although, of the published results, parents' level of optimism regarding their child's future and their ability to progress was guarded (Al-Dababneh, 2012).

Collectively, the current findings largely support the previous review (Hebert & Koulouglioti, 2010). Both highlight the wide variation in parents' etiological beliefs and that parents often held more than one belief. Whilst some of the variables that contribute to the formation of these beliefs were consistent in both reviews (e.g. symptom onset and culture), the current findings provide further insight. In particular, specific cultural influences and socio-demographic variables associated with beliefs are now better understood. In terms of parents' perceptions about the course of autism, both reviews found that expectations are associated with etiological beliefs. However, the current findings also indicated the significant role of socio-demographic factors in this area. Yet factors including finding a cure and improved societal acceptance of autism in relation to their future expectations were not mentioned, unlike in the previous review. The outcome of parents' beliefs were mostly consistent. For example, they impacted on maternal mental health, healthcare and reproductive decisions and were associated with parents' internal or external attributions. One finding that was not documented in the previous review, however, was the association between parents' beliefs and how this can alter their perceptions of the child. Finally, an area that has been largely extended compared to the previous review is the association between parents' beliefs and treatment selection. Overall,

whilst consistent findings are reported, the current review provides considerably more detail to enrich our understanding and allow for better comparisons with future reviews.

#### **4.1 Implications**

As discussed in the introduction, it is critical for clinicians to be aware of parents' beliefs. To summarise, the clinical implications are threefold; 1) open and honest discussions improve parent-professional relationships and may enhance parents' willingness to disclose information; 2) awareness enables clinicians to challenge known inaccuracies (e.g. the MMR-autism link) to ensure parents are well-informed about the evidence-base prior to decision-making; 3) providing information that resonates with parents' beliefs is more likely to be accepted and lead to positive change (Gona et al., 2015).

The introduction of discussing parents' etiological beliefs should form part of the standard diagnostic assessment protocol, and clinicians should remain aware of the variables that influence parents' views and beliefs as highlighted throughout this review. In addition, the findings from this review could also have implications for improving clinicians' awareness of parents' beliefs regarding other developmental conditions.

#### **4.2 Limitations**

A number of limitations relevant to the individual studies and this review require consideration. Individual limitations included methodological constraints, small non-generalisable samples and inappropriate measures (Table 2).

Many studies reported outcomes based on parental self-report. For example, confirmation of the child's diagnosis (Zuckerman et al., 2015, 2016) or outcomes such as altering their child's vaccination schedules (Bazzano et al., 2012). Studies would have

benefitted from stringent methodological protocols to clarify information using medical records.

As previously discussed, the use of adapted measures such as the IPA-R in Zuckerman et al., (2015, 2016) limit validity and reliability. Therefore, more accurate and consistent outcome measures would have been beneficial.

Participant response rate was rarely reported and a large proportion of studies recruited through advertisements at autism-related groups or re-contacting families from previous research. This may have caused bias in both sampling and parents' responses. Given the impact of community judgement in some cultures (Al-Dababneh et al., 2016) and the frequent use of researcher-administered questionnaires or interviews, participants may have presented socially desirable answers. This is also relevant to studies that exposed the research focus to participants. For example, parents in genetic-focused research may be more likely to endorse genetics as a causal factor of ASD (Goin-Kochel et al., 2015).

Regarding the review, the restricted inclusion criteria of studies published in a peer-reviewed journal and in English may have limited the findings. Furthermore, the wide range in samples, design and outcome measures utilised within the studies limited the authors' ability to assess the quality of the included studies and draw comparisons between findings. However, as the research in this area increases it would be beneficial for future reviews to address these issues. Additionally, as the literature search, study selection and data extraction were completed independently by the first author, consultation with a reviewing team may improve reliability.

### **4.3 Future Research**

Due to a number of limitations and unanswered questions further research is required. Firstly, almost all studies utilised cross-sectional designs. The one exception, Jegatheesan et al.,

(2010), used a longitudinal design, however the findings did not report on the stability of beliefs over time. Many of the studies also failed to report the time period between diagnosis and asking parents about their beliefs. Therefore, as beliefs are susceptible to change and can evolve as a consequence of external influences such as the media or through interactions with others, longitudinal or follow-up data should be collected. This would provide further insight into the extent to which beliefs can change and factors associated with change, both of which are vital for clinicians to be aware of, in order to support open and ongoing discussions with parents.

Secondly, more research is needed to explore gender-related variations including: 1) the etiological beliefs and expectations of fathers, as samples were mostly dominated by mothers; and 2) whether parents' perceptions differ according to the child's gender. Understanding how culture is associated with these outcomes would be helpful. Particularly as parents in some cultures hold strong expectations about their child's future occupation or family role according to their gender. Therefore, the potential interference of an autism diagnosis may impact on their ability to accept the diagnosis and readjust expectations accordingly. With reference to culture, whilst the included studies were geographically diverse, there remains a need for future research to explore cultures that were not considered within the current review.

Additionally, whilst the research has highlighted the importance of clinicians asking parents about their beliefs, expectations and treatment preferences, further research to evaluate the impact and effectiveness of this is essential. This knowledge is invaluable if best practice guidelines are to be developed.

#### **4.4 Conclusion**

This review highlights that parents hold a range of etiological beliefs about autism and that these beliefs are somewhat influenced by culture and socio-demographic variables. The

methodological limitations and variation in studies make it difficult to provide an accurate and valid conclusion regarding the most widely accepted beliefs and their associated implications. Nevertheless, the insights have been valuable in order to raise awareness of the importance of clinicians inquiring about parents' beliefs. Future research to compensate for limitations should contribute further to the development of best practice guidelines in this area and for other developmental conditions.

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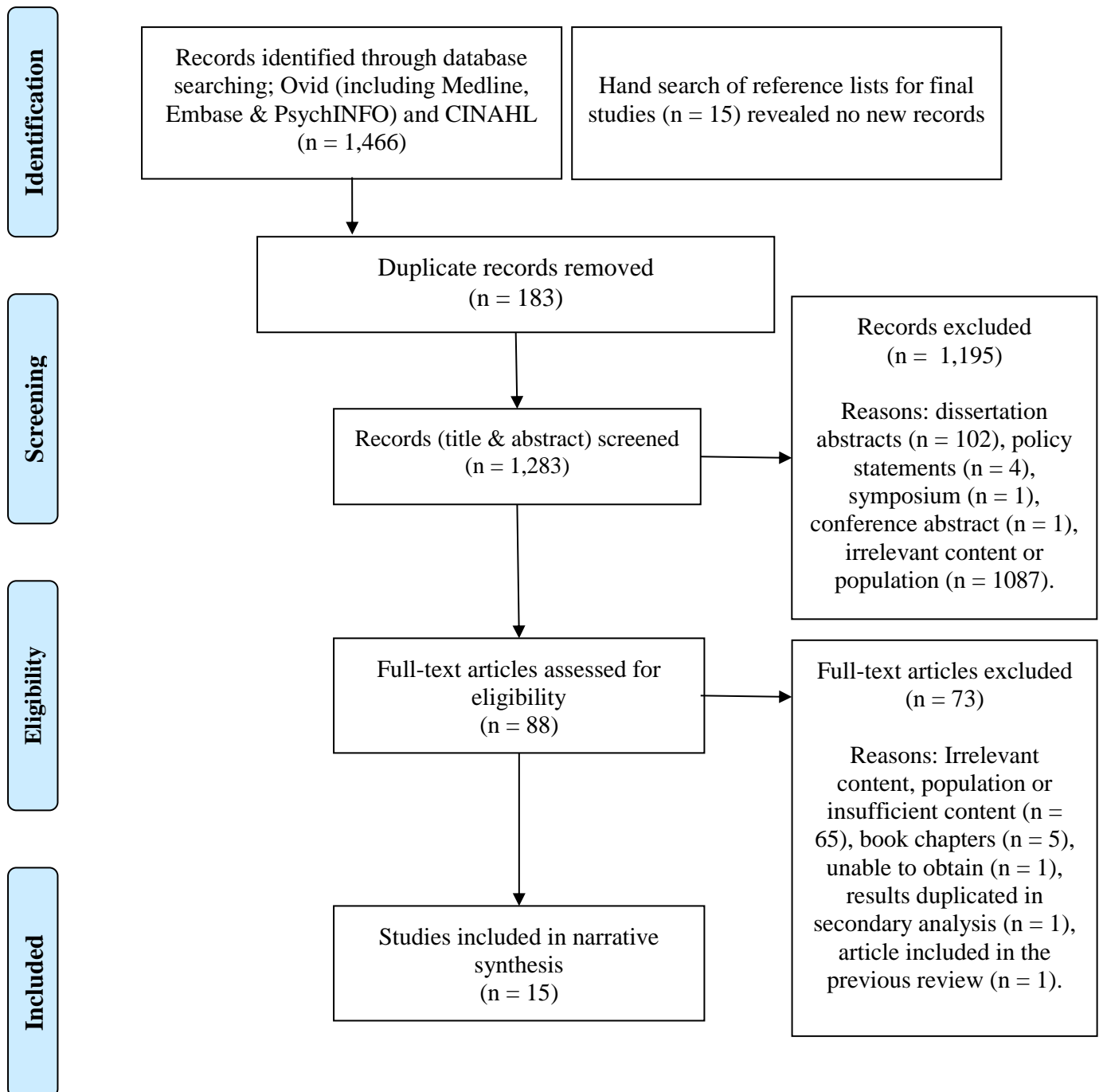


Figure 1. *PRISMA diagram outlining the study selection process (adapted from Moher, Liberati, Tetzlaff & Altman, 2009)*

Table 1.

*Study Characteristics*

Author / Year	Country	Sample (Response)	Recruitment Method	Parent			Children		Data collection	
				Status / Age	Education	Household Income	Religion / Ethnicity	Gender / Age		Diagnosis
Jegatheesa n, et al., (2010)	USA	6 (3 families) (n.a.)	Professionals identified 2 families, final family identified via contacts of the selected families	3 Mothers, 3 Fathers; 30-49 years		\$20-60,000 annually	Sunni/Muslim (n=2 families), Shai/Muslim (n= 1 family)	3 Boys; 5-6 years	Sample limited to autism; Diagnosis age: 5-6 years	Longitudinal, Ethnographic. Face-to-face or telephone conversational interviews
Shyu et al, (2010)	Taiwan	13 (n.a.)	Identified via psychiatry clinic and autism day care settings	12 Mothers, 1 Father; 34-45 years (m=37.4 years)	<College (n=3), College (n=4), University (n=4), Masters degree (n=2)		Buddhism (n=5), Taoism (n=3), Folk beliefs (n=3), None (n=2)	100% Boys	Mental retardation (n=9); Diagnosis age: 2-4years (m=2.6years)	Semi- structured face-face interview
Wasserman et al., (2010)	USA	13 parents (ASD); 36 parents (schizophrenia) (n.a.)	Emailed from 'Autism and Related Research' university database	11 Mothers, 2 Fathers; 36-66 years (m=56.8 years) <sup>a</sup>			Caucasian (n=8), Hispanic (n=5) <sup>a</sup>	10 Males, 3 Females; 18-24years (m=26.2 years) <sup>a</sup>	Sample limited to high functioning autism or Aspergers	Interviewer administered questionnaire (CDS) and 5- minute speech sample
Dardennes et al., (2011)	France	78 (n.a.)	Advertised through autism websites and parent groups	57 Mothers, 18 Fathers, 3 Primary Caregivers	12-31 years (m=16.4 years)	65.4% had income considered enough for living		60 Boys, 18 Girls; 2.3-44.5 years (m=13.5 years)	Autism (59%) PDD-NOS (21.8%) Aspergers (15.4%) Unspecified (3.8%) Diagnosis age: 8months-35 years (m=5.5 years)	Mailed Questionnaire (LBA-Q).

Alqahtani (2012)	Saudi Arabia	47 (82%)	Purposive sampling from medical center, contacted via phone	22 Mothers, 25 Fathers; 27-57 years	Primary (n=8), Secondary (n=13), Higher (n=30)		26 Boys, 21 Girls; 3-15 years	Sample limited to autism Diagnosis age: 1.5-3 years (n=15) 4-5 years (n=25) >6years (n=6)	Face to face semi-structured interview
Bazzano et al., (2012)	USA	197 (43%)	Part of a larger survey		≤ High school (n=41) College (n=22) College graduate (n=71) University graduate (n=63)	Caucasian (n=91), Hispanic/Latino (n=52), African American (n=26), Other (28)	159 Boys, 38 Girls; <18 years	Autism (n=165) Asperger (n=12) PDD-NOS (n=12) Diagnosis age: 11months-13 years (m=2.8 years) Severity: Low (n=60) Medium (n=79) High (n=39) Unsure (n=19)	Telephone survey
Bilgic et al., (2012)	Turkey	172 (n.a.)	Families approached in medical centers across five locations		Mothers education (m=7.8 years); Fathers education (m=9.1 years)	≤ \$330 monthly (n=14), \$330-660 monthly (n=51), \$660-1,320 monthly (n=61), \$1320-1980 monthly (n=33), > \$1980 monthly (n=12)	139 Boys, 33 Girls; <18 years (m=8.8 years)	Autism (n=146) PDD-NOS (n=24) Aspergers (n=2); (m=5.6 years since diagnosis)	Interviewer-administered questionnaire
Ravindran & Myers (2012)	USA Canada Kuwait	24 (n.a.)	Advertised on autism websites and support groups	21 Mothers, 3 Fathers; 27-14 years (m=36 years)	90% ≥ Bachelor degree	50% earned US\$90,000+ per year	Hindu (n=18) Jain (n=1), Christian (n=1), unreported (n=3). 21 Boys, 3 Girls; 3-15 years (m=7.3 years)	Autism (n=20), PDD-NOS (n=4) Severity: Mild (n=12) Moderate (n=10) Sever (n=1) Unreported (n=1).	Online / telephone semi-structured questionnaire

Chen et al., (2015)	Taiwan	39 (n.a.)	Recruited via Autism groups (one of which was lead by the author)	31 Mothers, 8 Fathers; 34-52 years (m=42 years)	≤ High school (n=9), Some college (n=6), ≥College graduate (n=24)	<US\$20,000 (n=13), US\$20,000- US\$33,000 (n=13), ≥US\$33,000 (n=13)	None (n=6), Buddhism (n=21), Folk (n=7), Taoist (n=5), Christian (n=5), Other (n=4)	40 children (one parent had two children).	Sample limited to autism Severity: Mild (n=24) Moderate (n=13) Severe (n=3)	Face-to-face semi-structured interview
Goin-Kochel et al., (2015)	USA	68 (n.a.)	Re-contacted following participation in SSC			<\$20,000-\$50,000 (n=13), \$51,000-\$100,000 (n=22), \$101,000->\$161,000	African American (n=5), Asian (n=4), White (n=50), Hispanic (n=16)	59 Boys, 9 Girls; 4.2-17.8 years (m=9.2 years)		Mailed Questionnaire (IPQ-R)
Gona et al., (2015)	Kenyan Coast	51parents 52professionals (n.a.)	Purposive-convenience sampling, via clinics and educational resource centres	2 Locations: Mombasa (n=21), Kilifi (n=30); 25-75 years <sup>a</sup>	≤ Secondary school (n=51) <sup>a</sup>		Traditional, Christianity, Islam <sup>a</sup>		No formal measure of autism in Kenya, presumptive diagnosis used.	In-depth interviews and focus groups
Zuckerman et al., (2015)	USA	1420 (n.a.)	Recruited via the Pathways survey and the 2009-10 (NS-CSHCN)		≤ High school (n=200), >High school (n=1220)	0-99% Federal poverty level (FLP) (n=198), 100-199% FLP (n=277), 200-300% FPL (n=475), ≥400% FPL (n=470)	White non-Hispanic (1056), Hispanic (n=118), Black, non-Hispanic (n=89), other (145)	1155 Boys, 264 Girls; 6-17 years	Autism, Asperger's, PDD-NOS	Interviewer administered IPQ-R.
Zuckerman et al., (2016).	USA	1420 same as above (n.a.)	As Above		As Above	As Above	As Above	As Above	As Above	As Above



Al-Dababneh et al., (2016)	Jordan	15 - represents 24% of full sample. (n.a.)	Recruited via educational settings	Parents of children with ASD extracted so individual characteristics unknown <i>Full sample</i> <sup>b</sup> : 54 Mothers 9 Fathers 18-≥54 years	<i>Full sample</i> <sup>b</sup> : Primary school (n=10), Secondary school (n=31), ≥College (n=22)		<i>Full sample</i> <sup>b</sup> : 35 Boys, 28 Girls; 6-8years (n=19), 9-12 years (n=25), 13-16 years (n=19)	Mild-moderate autism (n=15) extracted from sample.	Face-to-face semi-structured interviews
Fischbach et al., (2016)	USA	502 parents (91%)  60 scientists (80%)	Families re-contacted following participation in SSC.	476 Mothers, 26 Fathers; 39-47 years (m=43 years)	≤ 8 <sup>th</sup> grade (n=1), High school (n=1), High school graduate (n=32), College (n=112), College graduate (n=192), >College (n=164)	White (n=409), Hispanic/Latino (n=39) Asian (n=24), Black/Non Hispanic (n=19), Native American (n=8), Hawaiian (n=3).		Autism (n=262), PDD-NOS (n=137), Aspergers (n=86), ASD (n=6), High functioning (n=5), Other (n=5), Unreported (n=1)	Telephone interviews

ASD: autism spectrum disorder; PDD-NOS: Pervasive developmental disorder – Not Otherwise Specified; SSC: Simon Simplex Collection (a large American dataset of 2700 families who have one child aged 4-18 years with ASD and where ASD is absent in siblings or parents); LBA-Q: Lay-Beliefs about Autism Questionnaire; NS-CSHCN: National Survey of children with special health care needs (data collected three times between 2001-2010); CDS: Causal Dimension Scale; IPQ-R: Illness perception questionnaire revised for autism.

<sup>a</sup> Sample characteristics refer to parents of children with ASD only.

<sup>b</sup> Full sample included 3 groups of children with either ASD, intellectual disabilities or specific learning disabilities.

Table 2.

*Summary of findings*

Author / Year	Research Focus	Measurement Method	Findings			Limitations
			Parental beliefs about the cause(s) of ASD	Parental beliefs about the course of ASD	Cause / Implications of parental beliefs	
Jegatheesan et al., (2010)	Examine parental beliefs about ASD and future goals.	Conversational interviewing over 17 months. Mothers interviewed 8 times (15hours). Fathers interviewed 5 times (8hours).	Allah chose family to raise “his special child”. Beliefs also attributed to fate and karmic connection: one family believed the mother and child were reincarnated to have ASD/parent the child with ASD due to events in their past life.	All parents held positive expectations of their children. Two themes emerged for parents’ goals: full inclusion into everyday life and into their multi-lingual world.	Due to the belief that ASD was a gift from Allah, parents’ objected to professionals highlighting the child’s deficits rather than their accomplishments. This presented conflict in treatment decisions. Parents believed the child should be integrated into the multilingual community. Whereas professionals advocated that teaching the child basic interactions in one language would facilitate their development.	Small sample. One of the families was recruited through participant’s contacts. Interviewer spent 17 months with the families, this could have impacted on the findings.
Shyu et al., (2010)	Examine Twainese parents’ EMs (beliefs and treatment selection).	Open-ended questions.	100% endorsed biological factors (including genetics and brain damage in pregnancy), 84.6% supernatural causes, 46.2% nutrition deficiency, 7.7% mercury-containing vaccines.	Future worries: child’s welfare, societal role, voting and inheritance rights.	Treatment choice was associated with causal beliefs. Supernatural beliefs were associated with seeking advice from fortune-tellers. Many parents would try any treatment due to the unknown etiology.	Small sample, one area in Twain. Sample were all young children. Diagnosis unconfirmed.
Wasserman et al., (2010)	Explore etiological beliefs about ASD and the impact on attributions towards their child. A comparison between parents of children with autism vs schizophrenia.	Agreement with listed symptoms, causes and attributions; revised CDS. Criticism was assessed via a five-minute speech sample.	Parents of children with autism: 77% cited genetics or genetics combined with other factors as the primary causal factor. Causes of ASD cited in order of frequency: genetics (n=4), combination of genetics and other factors (n=4), organicity (n=2), parental drug use (n=1), birth complications (n=1), and prenatal injury (n=1).		Parents of children with ASD made less critical and blameworthy attributions about their child compared to those with schizophrenia. Diagnosis of ASD at a younger age, compared to schizophrenia, contributed to parents’ perception that it was beyond the child’s control and were therefore less critical towards them. Parents of adults with ASD rated genetics as the most significant causal factor, unlike parents of those with schizophrenia. Again this contributed to parental perception that if the disorder is biological it is beyond the individuals control.	Small sample. In the comparative data – the effect size reported moderate differences between attributions made by each group, yet statistical significance was not found through a test of mean differences. This could be explained by the small sample. Onset age was not measured and could have explained between group differences.

Dardennes et al., (2011).	Examine the relationship between causal beliefs about ASD and associated treatment choices.	1. Agreement with 24 named causes. 2. Open-ended question: Parents cite their top 3 etiological beliefs.	1. Most common belief was brain abnormalities (m=6.04), followed by genetics (m=5.65). Parents neither agreed or disagreed with chemical imbalance (m=4.38). Other, less cited, factors included food allergies (m=3.43), pre-natal illness (2.81), early trauma (m=2.73) as rated on a 7-point scale. Etiological beliefs of poor parenting were rejected. 2. 88% freely cited beliefs. Most common were 1) genetics; 2) heredity; 3) hazard. Vaccines, diet, immunity dysfunction, toxins and pollution were cited, but only by 1-3 parents.	Causal beliefs are associated with treatment choice. Parents who believed in early trauma were less likely to use behaviour therapy and PECS. Beliefs of pre-natal illness increased the use of prescribed medication. Beliefs about food allergy increased association with detoxifications treatments, special diets and vitamins, but reduced the likelihood of drug use. Vitamin's were negatively associated with beliefs about brain abnormalities.	Likert scale.
Alqahtani (2012)	Explore parents' etiological beliefs about ASD.	Open-ended questions	Causes were listed as themes and illustrated by quotes. Most frequently cited causes were medical investigations during pregnancy, cultural causes (evil eye or victim of black magic) and vaccines. Other causes include; difficulties / vitamin deficiency during pregnancy, neurological deficit, poor emotional parenting, childhood trauma, lack of breast feeding.	Beliefs influenced by treatment outcome. Some parents cited medical explanations but retracted this when medical interventions were unsuccessful. Parents, mostly mothers, felt guilty for causing their child's ASD. All cited treatments were cultural (e.g. reading the "Al-Quran") except autism-diets or hyperbaric oxygen therapy. More than half of parents used gluten-casein-free diet, yet diet was not cited as a causal factor. No parent cited genetics - potentially due to social stigma.	82% response rate – 15 felt uncomfortable discussing the topic and thus may have held alternative views. Religious explanations are commonly accepted in Saudi to cope with unexplained medical disorders.
Bazzano et al., (2012)	To determine the impact of parents' etiological beliefs on vaccine decisions.	Multiple choice and open-ended questions.	Even split between parents' who did and did not believe vaccines caused ASD. Parents who vaccinated their child prior to diagnosis were more likely to state vaccines as the cause. Latino and African American and highly educated parents were more likely to endorse vaccines than Caucasian parents.	Over half of parents altered or discontinued vaccine schedules. 63% who believed that vaccines caused ASD changed doctors, 47% altered vaccine practice, 34% discontinued. No association between altering or discontinuing schedules and parents' education or insurance status. Caucasian parents more likely to change or discontinue vaccination schedules.	Limited response rate. Sample from one geographic location. Self-reported outcomes, vaccine records not checked.

Bilgic et al., (2012)	Examine the use of conventional and CAM treatments, and explore parents' etiological beliefs about ASD.	Open-ended questions.	Genetics/congenital (43%), birth complications (46%), poor parenting (20%), toxicity of mercury (14%), vaccines (16%), food (8%), physical trauma (8%), infection (8.8%), antibiotics (3%), prematurity (5%), medical interventions or physician mistakes (5%), febrile convulsion (4%), destiny (4%), other (14%), no idea (10%). (NB. Parents could cite multiple factors, hence total percentage exceeds 100).	99% used conventional treatments. 56% used CAM – most prevalent = spiritual healing, food supplements, diet and vitamin supplements. The economic burden of CAM use was very high. Parents who cited genetic/congenital factors as the primary cause were less likely to use CAM. Parents who cited vaccines were more likely to use CAM.	Parent demographics unreported. Face-to-face interviews in a hospital setting may present demand characteristics. Parents may have been more inclined to cite biological factors to reduce risk of judgment.
Ravindran & Myers (2012)	Explore the influence of acculturation on parental beliefs and practices for Indian families living outside India in Western cultures.	1. Open-ended questions. 2. Agreement with named causes.	1. Open-ended responses: vaccines (25%), environmental and genetic/biomedical factors combined (38%), unsure (30%), genetics alone (1 parent), food allergy (1 parent). 2. Higher agreement with western cultural beliefs (92% environmental toxins/biological factors, 79% genetics, 75% vaccines), compared to traditional Indian beliefs (33% destiny, 29% karma, 17% mistakes in a past life).	58% drew on a combination of Western and Indian causal beliefs and treatments. 17% preferred Indian only, 17% preferred western only, 2 failed to answer.	Self-reported diagnosis. Likert scale. Small sample. Acculturation measured indirectly.
Chen et al., (2015)	Explore perceptions about genetics and recurrence risk amongst Taiwanese parents.	1. Agreement with genetics as a cause of ASD, and their child's ASD. 2. Agreement with perceived recurrence risk. (high, low, moderate, no risk or unknown).	1. 74.4% agreed genetics is a causal factor in ASD, 17.9% were undecided and 7.7% believed otherwise. Of the 74% who agreed; this was based on their family history (n=17), knowledge of other ASD families (n=6), media (n=3), intuition (n=3), self-research (n=2) and physician (n=1). When asked about genetics as a causal factor in their child's ASD, only 43% (n=17) agreed. The majority of these parents (n=14) had diagnosed family history and the remaining (n=3) had traits within the family history.	2. 38.5% reported high recurrence risk, most (n=13) would avoid / terminate future pregnancies. 23.1% reported low risk, 20.5% were unsure, 12.8% perceived no recurrence risk and 5.1% perceived risk to be moderate. Causal beliefs and perceptions of recurrence were based on family history, knowledge of other families, media, intuition and own research. Only one participant was informed by their physician.	All but one parent had only one child with ASD. Perception about genetics may alter for parents with more than one child. The influence of demographics variables was unreported.

Goin-Kochel et al., (2015)	To explore the association between parents' causal beliefs and patterns of symptom onset.	1. Open-ended questions. Parents cited three most important causal factors. 2. Agreement with named causes (IPQ-R)	1. Genetic/hereditary (42.6%), environmental factors (22.1%; 76.6% specifically stated toxins in vaccines). When the top three factors were considered together over 80% reported external causes, compared to genetics/hereditary factors reported by 60%. 2. Internal factors (75.8% genetics, 59.7% child's brain structure). External factors (46.3% God's will, 41.8% toxins in vaccines, 37.3% environmental pollution). 90% believed in 2 or more factors.		Observing a child losing skills contributes to parents' causal beliefs. Parents who witnessed regressive onset had significantly stronger agreement with toxins in vaccines being a causal factor and a trend for stronger agreement with environmental pollution.	Parent demographics unreported. Sample from one geographic location. Recruited from the SSC (study examined genetic causes in families). This could have biased genetics responses. Onset measured by parents' retrospective self-report.
Gona et al., (2015)	Explore parents and professionals perceptions about causes and treatments of ASD in a multicultural context.	Open-ended questions.	Preternatural causes (curse, witchcraft, evil spirits), biomedical causes (infection, drugs, birth complications, malnutrition) or hereditary (genetics). All cited regardless of geographical location.	Parents hoped treatment was curative due to societal perspectives that ASD is a bad omen.	Treatments included traditional healers, prayers and medical interventions.	All participants from the Kenyan Coast. Limited number of participants without any formal education. Socio-economic status unreported.
Zuckerman et al., (2015)	Examine beliefs about the course of ASD in relation to ethnicity, income and educational attainment. Secondly, to explore whether beliefs are influenced by service utilisation and healthcare quality.	Agreement with 4 named causes (IPQ-R). Agreement with service utilisation and social determinants of health (race, income and parental education).		70.8% "definitely" believed difficulties were lifelong. Parents of Hispanic children were less likely to believe the condition was lifelong compared to parents of white children. 81.5% agreed the condition could be prevented / reduced with treatment. 44.5% thought the condition was a mystery. 44.8% agreed they had the power to alter the condition.	ASD health disparities were mostly not related to parental beliefs. Parents with lower income believed the condition was a mystery and were less likely to believe it could be prevented, treated or that they had the power to change it. High parental education was associated with a tendency to believe it could be prevented / reduced with treatment and less likely to believe it was a mystery.	Parent demographics unreported. Sample recruited from previous research (Pathways survey). All children had ASD but could also have other developmental disorders. Therefore, as the study asked about the cause of the child's learning/developmental difficulties, responses could have been related to other conditions. Other potential influences (e.g. media, health literature or social networks) were unreported.

Zuckerman et al., (2016).	Assess parents' etiological beliefs about learning and developmental difficulties in children with ASD. Secondly, to assess whether socio-demographic variables are associated with beliefs.	Agreement with 4 named causes (IPA-RA).	66.3% of parents definitely or somewhat agreed with genetic/hereditary causes. 41% somewhat / definitely agreed with post-natal exposure. 35.4% somewhat / definitely agreed with in utero exposure. Only 19.1% definitely agreed with accident / injury / illness. However, 80.9% definitely disagreed. 39.6% had no definite beliefs, 40.9% had 1 definite belief and 19.6 % held 2 or more definite beliefs.	Socio-demographic variables impacted on parental beliefs. Hispanic parents were less likely to definitely agree with genetic/hereditary factors compared to white parents (even after controlling for other variables). Parents of children with private, compared to public health insurance were twice as likely to somewhat agree (but not definitely agree) with genetic/hereditary causes. Non-biological parents were significantly more likely to endorse genetic/hereditary causes. Black parents and parents with low income were more likely to agree with post-natal exposure causes. Parents of children with private, compared to public, insurance were less likely to endorse post-natal exposure factors. Low income was associated with accident / illness / injury causal beliefs. No significant association was detected between child's age, gender or religion and parents' causal beliefs.	Same as above.	
Al-Dababneh et al., (2016)	Investigate parents' beliefs about the cause and course of their child's disability	Open-ended questions.	Biomedical causes (pre-natal risk factors, mothers age, stress, medication use during pregnancy and birth complications), genetics, early childhood illness, vaccines and the most common explanation cited by half of the parents was fatalism (ASD as a "gift from God").	Most held positive expectations about the child's potential progress. Some believed they would work and attend high school, but acknowledged the time / patience this required. Half were proud of their child's progress regardless of it's significance, others believed the progress level would not be satisfactory. Low expectations were related to vulnerability. Social and communication skills were the most important skills for a child to reach their potential.	Parents' causal beliefs impact on their beliefs about the course of their child's ASD. Some mothers felt responsible for causing their child's ASD due to their own carelessness or psychological stress during pregnancy. Their guilt may be a result of community attitudes.	Parents of children with ASD were extracted from the research only and therefore sample size is small. Furthermore, parent demographics are unclear for this subset of the sample. Due to the nature of qualitative research, results only comment upon generated themes, so the extent to which each parent held certain beliefs is unknown.

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Fischbach et al., (2016)	Investigate concordance between parents' and professionals' etiological beliefs about ASD.	Open-ended questions.	Parents' beliefs: genetic (55%), vaccines (13%), environmental toxin exposure (9%), parental age (3%), others (prematurity, diet, prenatal events, immune system, medication in pregnancy, environment-genetic interaction, 13%), unsure (7%). Scientists' beliefs: genetics (95%), toxin exposure (3%), other (maternal vitamin D deficiency, idiopathic autism, 2%).	Parents and scientists differed significantly, but had high agreement for genetic testing, disclosure of results and heightened levels of concern for future generations if a genetic cause is identified. Treatment was agreed as the most important goal of research. 37% of parents would hesitate getting a child vaccinated, 97% of professionals would not.	Parents recruited from the SSC. Homogeneous sample (predominantly white, high IQ).
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ASD: Autism Spectrum Disorder; EMs: Explanatory Models; PECS: Picture Exchange Communication System; CAM: complimentary and alternative medicine; SSC: Simons Simplex Collection (A large American dataset of 2700 families who have one child aged 4-18 years with ASD and where ASD is absent in siblings or parents); CDS: Causal Dimension Scale; IPQ-R: Illness perception questionnaire revised for autism.





*'Getting that Little Piece of Paper in Black and White'*

Parents' Experiences of the Autism Spectrum Disorder Assessment Process when the Child  
did not receive a Diagnosis.

SHORT TITLE: Experience of the ASD Assessment when a Diagnosis is not received.

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Cite references in the text by name and year in parentheses. Some examples: ☼ Negotiation research spans many disciplines (Thompson 1990).

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Slifka, M. K., & Whitton, J. L. (2000) Clinical implications of dysregulated cytokine production. *Journal of Molecular Medicine*, doi:10.1007/s001090000086

#### ☼ Book

Calfee, R. C., & Valencia, R. R. (1991). *APA guide to preparing manuscripts for journal publication*. Washington, DC: American Psychological Association.

#### ☼ Book chapter

O’Neil, J. M., & Egan, J. (1992). Men’s and women’s gender role journeys: Metaphor for healing, transition, and transformation. In B. R. Wainrib (Ed.), *Gender issues across the life cycle* (pp. 107–123). New York: Springer.

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Resource document. American Psychiatric Association. [http://www.psych.org/edu/other\\_res/lib\\_archives/archives/200604.pdf](http://www.psych.org/edu/other_res/lib_archives/archives/200604.pdf). Accessed 25 June 2007.

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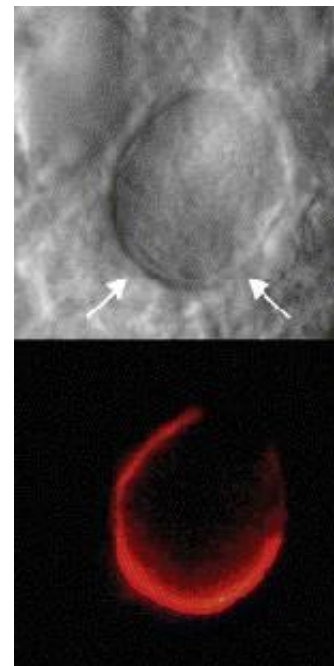
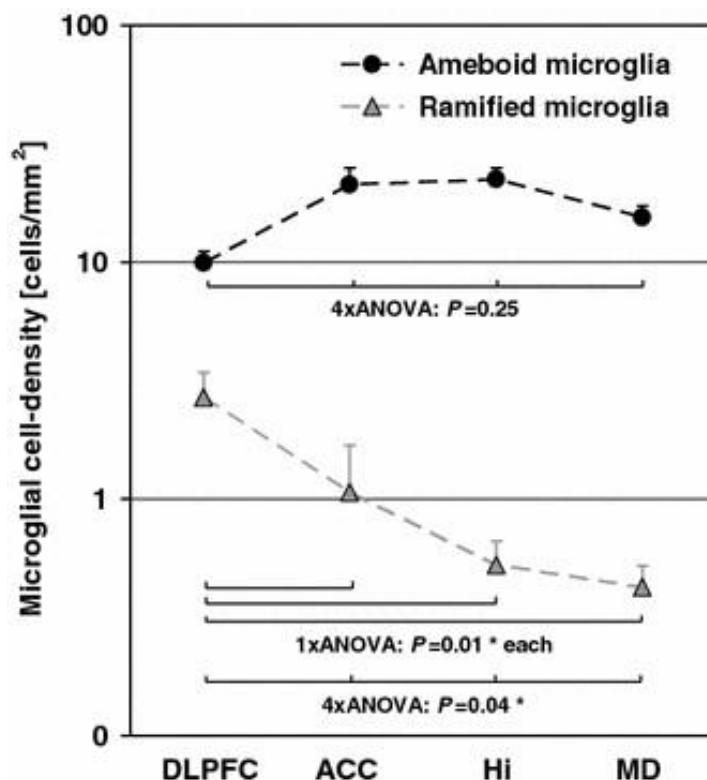
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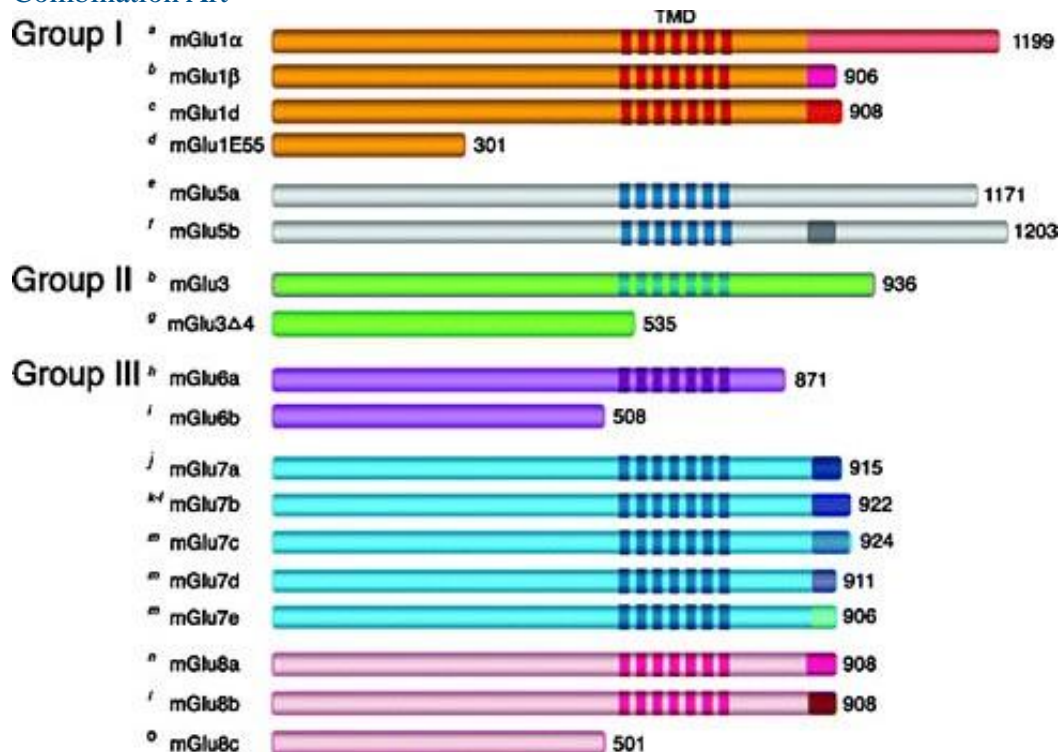
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### **Abstract**

The aim of this research was to explore parents' lived experience of the Autism Spectrum Disorder (ASD) assessment process when a diagnosis was not received. Six mothers and one step father were interviewed using a semi-structured schedule. The results were analysed using interpretative phenomenological analysis (IPA) through which three superordinate themes emerged: "My child *is* different"; the emotional and psychological journey; and understanding the outcome. These themes illustrated the issues that parents encountered during both the assessment process and in parenting a child with autistic-like characteristics but without a valid label. As this is an area that has been previously understudied, a number of clinical implications at the professional, service and policy level are discussed.

*Key words: autism, assessment, parents, interpretative phenomenological analysis.*

In recent years, recognition of Autism Spectrum Disorders (ASD) has become widespread. Advocacy organisations such as Autism Speaks and the National Autistic Society (NAS), have campaigned to increase awareness and acceptance of the disorder (Wallace et al., 2012). Some researchers argue that heightened awareness has contributed to increased prevalence rates, however opposing views propose influential factors such as earlier diagnosis, changes to diagnostic criteria and better resourced services (Matson & Kozlowski, 2011; Neggars, 2014). Nevertheless, one point of agreement is the increased number of families accessing diagnostic services for their children.

Many families initiate this process to gain a definitive diagnosis. Parents believe that classification of their child's difficulties will explain their missed milestones and unusual behaviours, helping them to better understand their child's needs (Avdi, Griffin & Brough, 2000). This understanding reduces parents' confusion and equips them with more realistic expectations for the future (Midence & O'Neill, 1999). Within the intellectual disability literature, Makela, Birch, Friedman and Marra (2009) assessed the perceived value of a diagnosis by comparing families with and without a diagnostic label. Several themes were noted, with the most common being 'validation', as this enabled parents to explain their child's difficulties using a recognised label.

Many children with autism, or autism traits, find it difficult to navigate social situations and the overwhelming accumulation of sensory information can lead to behavioural outbursts (Wigham, Rodgers, South, McConachie & Freeston, 2015). In a recent survey, 74% of families experienced disapproving noises from the public due to their child's behaviours, whilst 87% were subjected to staring (NAS, 2016). Yet, having a tangible explanation for their behaviours reduced the impact of critical bystanders and empowered parents to advocate for their child.

Other values of diagnosis identified by Makela et al., (2009) included access to

information, timely interventions and improved social support. Likewise, the perception that an ASD diagnosis permitted access to funding and therapeutic intervention was reported by Keenan, Dillenburger, Doherty, Bryne and Gallagher (2010). These factors were considered fundamental components in helping families to overcome uncertainty and achieve acceptance (Midence & O'Neill, 1999). Correspondingly, some families reported that the positives of gaining a diagnosis outweighed the negatives (Wong, Keyes & McGrew, 2016).

Despite the benefits associated with diagnosis, families described their experience of pursuing this as unsatisfactory. In a large UK survey (n=1295), Howlin and Moore (1997) found that 49% of parents were 'not very' or 'not at all' satisfied with the assessment process. Although this study was published twenty years ago, similar findings were reported in more recent literature. For example, in a sample of 56 parents, 51% were dissatisfied (Siklos & Kerns, 2007) and in a separate sample of over 1000 parents, 52% were dissatisfied (Crane, Chester, Goddard, Henry & Hill, 2016). Factors influencing parents' satisfaction included diagnostic delay, the number of professionals involved and professionals' communication (Watson, Hayes & Radford-Paz, 2011).

Parents who saw fewer professionals and received an early diagnosis were more satisfied with the process (Goin-Kochel, Makintosh & Myers, 2006). In their questionnaire study of 494 parents, they reported that on average, parents typically saw four or five professionals. Unsurprisingly, age at diagnosis was positively associated with the number of professionals seen ( $r = 0.15$ ,  $p = 0.002$ ) and negatively associated with satisfaction ( $r = -0.15$ ,  $p = 0.001$ ).

ASD can be diagnosed as young as two (Lord et al., 2006). However, Crane et al., (2016) found that parents typically waited 12 months to seek professional advice, and upon initial contact their concerns were often dismissed or referred onwards. Average time from first contact to obtaining a diagnosis was a further 3.5 years, with children typically being diagnosed

at 7.5 years (SD = 5.0 years). For many, this delay caused frustration relating to the missed opportunity for early intervention. Disappointingly, these results show no great reduction from the findings of Howlin and Moore (1997). The finding that professionals dismissed parents' concerns is unfortunate, as Brogan and Knussen (2003) found that families were more accepting of delays if professionals validated their concerns.

The frustration regarding assessment delays and lack of post-diagnostic support is shared by professionals (Rogers, Goddard, Hill, Henry & Crane, 2016). However, such delays are not always related to inadequate service provision. Autism is a complex disorder, as there is no medical test, and unlike other neurodevelopmental conditions such as Fetal Alcohol or Down syndrome, there are no physical symptoms to aid early diagnosis (*Diagnostic & Statistical Manual of Mental Disorders*, 5<sup>th</sup> ed.; DSM-5; American Psychiatric Association [APA], 2013).

Another factor influencing parent's satisfaction, was the parent-professional relationship and the quality of information provided by professionals. Moh and Magiati (2012) found that higher parental assessment satisfaction was associated with higher perceived collaboration with professionals. This was indicated by professionals acknowledging their concerns, collaborating in making decisions and discussing the diagnosis and post-diagnostic support. Likewise, feedback from 15 UK parent focus groups reviewing professionals' communication skills, advocated for more professional training to improve awareness, diagnostic competency, interpersonal skills for disclosing diagnosis and intervention knowledge (Osborne & Reed, 2008).

Generally, the experiences of parents whose child receives a diagnosis are well documented. Whilst it is clear that the assessment process can be distressing, parents often reported a sense of relief once the diagnosis was made (Avdi et al., 2000). Thus allowing them to work towards accepting the diagnosis (Midence & O'Neill, 1999).

However, little is known about the experience of parents who embark on the same prolonged and stressful assessment journey, but do not receive a diagnosis or the diagnosis is vague, for example, having autism ‘traits’ or ‘features’. In the limited ASD research available, these parents felt vague descriptions were unhelpful and reduced their assessment satisfaction (Howlin & Moore, 1997). Nevertheless, findings from the wider literature may be applicable. Lenhard, Breitenbach, Ebert, Schindelbauer-Deutscher and Henn (2005) found that mothers of children with Down syndrome, reported less emotional burden than mothers whose child had no specific diagnosis. Similarly, families of children with non-epileptic attack disorder reported distress during the assessment process and felt disbelieved by professionals (McWilliams, Reilly, McFarlane, Booker & Heyman, 2016). Furthermore, with medically unexplained diagnoses, parents struggled to accept the absence of a specific medical explanation (Moulin, Akre, Rodondi, Ambresin & Suris, 2015). These researchers speculated that parents’ uncertainty regarding the prognosis, unresolved concerns and a lack of professional recognition cause increased emotional burden and disrupted family functioning.

Therefore, this research aimed to explore parents’ lived experience of the ASD assessment process when a diagnosis is not received. To the researchers’ knowledge this is the first study to explore this objective. It is hoped that in addition to enhancing professionals’ understanding, the findings will inform service development to improve ASD assessments and consider how best to communicate a non-diagnosis outcome.

## **Method**

### **Study Design**

This research explored parents’ experiences of the ASD assessment process when their child did not receive a diagnosis. Interpretative phenomenological analysis (IPA) was

considered the most suitable qualitative methodology, as it allows detailed exploration of an individual's lived experience (Smith, Flowers & Larkin, 2009). IPA is informed by concepts derived from three fundamental areas of philosophy; phenomenology, hermeneutics and idiography (Pietkiewicz & Smith, 2014). Phenomenology (the study of experience) focuses on how parents perceive and talk about their assessment experience. Hermeneutics (the theory of understanding and interpretation) allows the researcher to explore the individuals' experience using their own interpretation. This analytic process is described as a 'double hermeneutic'; "the researcher is trying to make sense of the participant trying to make sense of what is happening" (Smith et al., 2009, p.3). The third concept, idiography, refers to the thorough analysis of each participants' perspectives, rather than drawing a conclusion of probability from a large group like most empirical research (Smith, Harré & Van Langenhove, 1995). Consequently, IPA employs small, purposively-selected samples and given the rich insight into individuals' experiences, IPA research is influential in clinical settings (Brocki & Wearden, 2006).

### **Ethics**

Approval was granted by the Health and Care Wales Research Ethics Committee (Appendix A and B), Bangor University School of Psychology (Appendix C) and Betsi Cadwaladr University Health Board (BCUHB) Research and Development Committee (Appendix D).

### **Participants**

A small purposive sample of parents (six mothers and one stepfather) of six children was recruited through a neurodevelopmental team in North East Wales, between November 2016 and February 2017. In line with IPA (Smith et al., 2009) the sample size was appropriate as this enabled in-depth examination of the parents' experiences. In IPA the sample must be

reasonably homogenous. Therefore, participants were recruited using the following criteria: they were over 18, had children aged 5-19 years who had undergone an ASD assessment in BCUHB between February 2016 and February 2017; they had attended the feedback appointment and were not given a diagnosis. Parents were excluded if they could not provide informed consent; their child was accessing professional support for other neurodevelopmental difficulties; they received an alternative diagnosis, such as Attention Deficit Hyperactivity Disorder or a Speech and Language Therapy diagnosis during the assessment.

### **Procedure**

Potential participants were identified and contacted via the clinician who conducted their child's assessment. Bilingual (Welsh and English) recruitment packs were provided and included a letter of invitation, participant information and an opt-in form (Appendix E, F and G). On receipt of completed opt-in forms, the first author contacted potential participants using a telephone protocol to discuss the research and arrange a time for interview (Appendix H). Fifty packs were prepared, however, as recruitment was conducted by clinicians it is not possible to determine a definitive response rate. Interviews were completed at the same clinic as their assessment and written informed consent was obtained from all individual participants prior to interview (Appendix I). A £10 voucher was provided as a gesture of appreciation for sharing their time and expertise.

To protect anonymity, participants and their children were ascribed pseudonyms. Table 1 displays participant characteristics.



Table 1.

*Participant Characteristics*

<b>Participant*</b>	<b>Parental Status</b>	<b>Child*</b>	<b>Child's Gender</b>	<b>Age at assessment</b>	<b>Age at first concern</b>	<b>Person who raised concern / requested assessment</b>	<b>Approximate interval between feedback and interview</b>
Jane	Mother	Oliver	Boy	5 years	3 years	Mother	4 months
Melissa	Mother	Erin	Girl	12 years	2.5 years	Professional then mother	5 months
Martha	Mother	George	Boy	8 years	5 years	School Teacher then mother	3 months
Emma	Mother	James	Boy	4 years; 9 years <sup>***</sup>	9 months	Mother	6 months
Vicky Paul <sup>**</sup>	Mother Step Father	Charlie	Boy	9 years; 13 years <sup>***</sup>	8 years	Mother	12 months
Sarah	Mother	Henry	Boy	15 years	15 years	Professional	3 months

\**Pseudonyms*

\*\**Parents interviewed together*

\*\*\**Second assessment*

## **Data Collection**

Face-to-face semi-structured interviews were conducted in English over a four-month period by the first author. Interviews were audio-recorded and ranged from 36 to 80 minutes in length. Six interviews were conducted in total, five individual interviews (mother only) and one joint interview (mother and step father). As suggested by Smith and Osborn (2003), interviews were guided by a schedule, although participants' experiences were explored further where necessary (Appendix J). The schedule was developed by the authors and reviewed by the neurodevelopmental team. Following recommendations from Elliott and Timulak (2005) field notes to record observations and reactions were produced during each interview to aid initial coding. Audio-recordings were transcribed verbatim and included vocalisations, pauses and laughter. All identifying information was removed or anonymised.

## **Data Analysis**

In accordance with the hermeneutic phenomenological approach, interviews were transcribed and analysed consecutively by the first author. Following guidance from Smith et al., (2009), the author read and re-read each transcript to become immersed in the data. A line-by-line analysis was subsequently undertaken and three types of exploratory comments (descriptive, linguistic and conceptual) were added to each transcript to enable the identification of abstract concepts (Appendix K). Similarities between concepts were highlighted to identify emergent themes, which reflected shared meanings within the individual's experiences (Appendix L). This process was applied to each transcript and a table summarising emergent themes and illustrative quotes was produced (Appendix M and N). The final stage, a cross-case analysis, involved searching for similarities between the transcripts to generate superordinate themes. All stages of the analysis were completed manually.

## Quality

To ensure the study was conducted to a high standard, an evaluative framework for qualitative research was consulted during the design phase (Yardley, 2000; 2015). Additionally, the first author wrote a reflective diary to record subjective thoughts or assumptions. This allowed the researcher to explore the personal impact of the process, promote transparency and consider how this might influence the analysis. The data was predominantly analysed by the first author, with one transcript analysed simultaneously by both authors. The analysis of additional transcripts and emerging themes were discussed during regular consultations between authors.

## Results

Three superordinate themes emerged: 1) “My Child *is* Different”; 2) The Emotional and Psychological Journey; 3) Understanding the Outcome. Themes are displayed in Table 2.

Table 2.

### *Summary of Themes*

<b>Superordinate Themes</b>	<b>Subthemes</b>
“My Child <i>is</i> Different”	Emphasising Difference
	Talking about and Disclosing Difference
	Celebrating Difference
The Emotional and Psychological Journey	Alone
	Judged
	Impact on self
	Unrelenting Battle
Understanding the Outcome	Lack of Closure
	Relief
	The Future

## “My Child *is* Different”

**1. Emphasising Difference:** All parents acknowledged or described their child as different. Some parents described their child as “non neuro-typical”, “complex”, “not normal”, or listed characteristics which set their child apart. As illustrated by Melissa, noticing disparities with other young people was often the catalyst for parents identifying, and later accepting, their child as being “different”.

I could see she was emotionally quite behind (...) I sort of made excuses for it a bit y’know and sort of at high school everyone was boyfriends and makeup and all that and she wasn’t and I could just really notice – Melissa.<sup>1</sup>

Other parents emphasised their child’s differences by recognising their similarities to children with a diagnosed neurodevelopmental condition. They also used the severity of symptoms and diagnostic label as a benchmark for interpreting their own child’s differences.

I’m not saying that he has got a very bad case of it (...) I’d say he is...he he has...he shows traits (...) my brother’s son had autism (...) he didn’t speak until about five years, so I know there is extreme cases. Charlie’s not like that (...) but he is...he does have the traits of it...I watch the programme *The Undateables*<sup>2</sup> and there are sometimes some characters in that and I’ll go “that’s Charlie!” – Vicky.

For Vicky, the possible variability in presentation caused some confusion. To her, Charlie’s characteristics were synonymous with people diagnosed with autism, and whilst she

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<sup>1</sup> Transcript conventions will be used throughout: ... speech hesitation; (...) words removed.

<sup>2</sup> A television programme about people with often-misunderstood conditions, such as autism.

appreciated the spectrum of symptom severity, she believed the similarities were compelling. Consequently, she was confused and frustrated as to why Charlie had not received a diagnosis. This is detected through the repetition and hesitation in her quote. Like Vicky, many parents affirmed that they knew their child best and by emphasising the differences, were attempting to highlight their need for diagnosis.

**2. Talking about and Disclosing Difference:** Most parents did not want their child to be defined by a “label”. However, this provided them with a dilemma of how best to describe their child’s difficulties.

I hate using the word different or not normal but it’s the only language I’ve got – Emma.

Emma further illustrated that her lack of knowledge about how to explain her child’s differences were also experienced by her son. This appeared to be a painful experience for both of them, and indicates how powerless Emma feels as a mother and being unable to explain his experiences to him.

He will say, “I know mummy that my mind isn’t built like everyone else, but I can’t cope with it” which is difficult to hear – Emma.

Some parents reflected on the dilemma of disclosing their child’s differences as a way of preempting potentially difficult situations. Jane reported “you’re constantly battling between do I point out that he is different or do we wait until there’s a crisis?” Alternatively, Melissa described that without a valid label, preempting such situations is futile.

I'd gone to the high school before and said these are Erin's traits (...) this is what she's going to have difficulty with (...) they said "oh we have lots of people like that". So I think because there wasn't any specific diagnosis (...) they just thought I was like a worried mum – Melissa.

**3. Celebrating Difference:** Parents acknowledged that their child's differences formed their character and made them who they were.

Even though I want to take all this away from him, actually I don't because if I did that he wouldn't be my James – Emma.

He's super clever where the computer is concerned. He's designing his own games (...) and he's like "I'm going to go and work for Google" and I'm like 'you're going to own Google' (...) that makes me feel really happy (...) I couldn't be prouder – Vicky.

Throughout the interview Vicky highlighted her son's fascination with computers as an "autistic trait" and something which impacts negatively on his ability to make friends. Yet this quote illustrates her recognition that this unique attribute sets him apart from others in a positive manner and should be celebrated.

### **The Emotional and Psychological Journey**

**1. Alone:** Throughout the journey, many parents felt alone. Some reported feeling marginalised by friends due to their child's behaviour or their lack of time for socialisation. Others perceived their loneliness to be the result of their concerns being dismissed.

Loneliness was predominantly experienced at the beginning of the journey as parents interpreted symptoms differently. Emma stated “my husband was in denial for a lot of the time”. She reflected on how difficult this was for her, but interpreted his optimism as a disguise for fear of “stigma”. Martha’s views also differed to her husband’s, however, she interpreted this as “mother’s intuition” and deemed it was her responsibility to seek support. The quote below demonstrated that other parents reflected more on their feelings of loneliness after the assessment.

We’ve just been left (...) I feel like I’ve been blindfolded and put in the most peculiar maze ever and I can’t find my way out and I’m trying to get to Charlie...and I can’t, I can’t get to him, because I...try and help him but he just doesn’t understand and that’s frustrating, that’s why as a family we need help – Vicky.

Vicky’s use of a metaphor emphasises her feeling of being abandoned due to a lack of professional support. Her quote demonstrates a sense of ambivalence too; she wants to get out of the maze while being aware that Charlie is stuck in the maze. There is a sense of feeling lost, hopeless and that everybody in the family needs guidance, as they are struggling to understand and communicate with him. Her words “I’m trying to get to Charlie and I can’t” gives a sense of Charlie’s loneliness and isolation too.

If you’ve got a diagnosis they say right, we’ll take you on all these training courses (...) but if you’ve got a diagnosis of non neuro-typical (...) you sort of drift and you’re alone. There’s no counselling (...) or no one to talk to, because you can’t talk to your husband cos it’s painful – Jane.

Jane illustrated her belief that gaining a diagnosis would have prevented the feeling of being marginalised by professionals. She also highlights the emotional impact of parents feeling unable to support each other and how this can exacerbate feelings of loneliness.

Parents placed a high value on a shared identity. However, most participants reported to seek support and shared experiences from outside the family due to the heightened emotional impact within the immediate family. Jane, who had a supportive family network, reflected that parenting a child with autistic traits and undergoing assessment was “the undoing of a lot of families!” Although she and her husband struggled to comfort one another, she valued the supportive aspect of attending “groups with other children with special needs”. Similarly, Emma valued the support and friendship of a mother whose son had autism, stating “that’s the one positive thing that’s come out of this.” This demonstrates the importance of belonging, acceptance and sharing this experience with others. Many parents felt that having a diagnosis to explain their child’s unique behaviours would offer commonality with other parents.

**2. Judged:** The majority of parents worried about whether their concerns would be validated. This was heavily influenced by the perceived judgment or “paranoia” they would receive in the event that a diagnosis was not given.

I did say to Dr A I hope you don’t think this is some sort of Munchausen by proxy thing. I’m not afraid to say that [laughs]. I’m afraid that you think that (...) because obviously Oliver had been in and out of hospital for lots of reasons, medical reasons, and of course when it’s medical you can see it can’t you? – Jane.

Judgment or “paranoia” is driven by fear and anxiety, as illustrated in Jane’s quote. She was anxious that due to a lack of visual symptoms her concerns would be disregarded.



Consequently, she feared that professionals would judge her for fabricating her son's symptoms. Jane's own use of the phrase "Munchausen by proxy" suggests that naming this openly would provide a level of control over this thought and ease her anxiety of this being considered by others. Her laughter, however, demonstrated that she felt uncomfortable about raising the topic.

I was so apprehensive because I thought if she turns around and goes nah there's nothing wrong with him, then I thought it's going to be all in my head, but when she said she might see him like very low on the spectrum I thought oh at least she is seeing something – Martha.

Martha's quote highlights the extent to which parents are affected by the perceived judgment of professionals not validating their concerns. Martha initially felt there was no need for the assessment, but requested it to satisfy the school's concerns. Nevertheless, she was relieved that "something" of concern was identified, as this alleviate the burden of it being in her head.

Because he hasn't had a diagnosis I kind of get the feeling that other people think...erm it's just in her head because they've said there's nothing you know...clearly wrong there...she's just making it up, or...it used to be really really hard to deal with. Now as time's progressing I kind of think "well stuff what anyone else thinks" - Emma

Emma illustrated that she had learnt to manage her worries about being judged and recognised this as an area of self-growth. Whilst diagnosis is not appropriate in all cases, the importance of feeling heard was valued. One mother stated "I had a good experience with Dr

C, he listens and doesn't say no you're wrong or that's not it, it's easier when you have a "it doesn't fit", it's easier because people have actually listened".

**3. Impact on self:** Throughout the interviews all parents described a great sense of responsibility. This was largely due to their own expectations of how they "should" react and their desire to feel in control of the situation.

Horrendous, just horrendous. I felt helpless. As his mother, I should be able to help him and I couldn't. I couldn't take it away from him. Whatever it was I couldn't take it away. I couldn't help him – Emma.

Emma's use of the words "horrendous", "helpless" and repetition of "I couldn't" illustrate the strong emotional impact on parents when they were unable to meet their own expectations of parenting.

Some parents described the multifaceted roles of being a parent, including being "an investigative journalist", "the best most organised diary keeper", "an advocate", a "teacher" and a "therapist". Trying to fulfill these roles could be a way of trying to gain control and minimise the feeling of hopelessness. However, parents highlighted that this required sacrificing other commitments to focus on supporting their child. Having this level of involvement in the child's life, presented difficulties for parents during the assessment process. They described their emotions as "bubbling up" and felt they had to "put a lid on them" to present the child's case coherently.

The pressure of 'getting it right' differed between parents. Sarah described the assessment as "a lot of pressure", because she "didn't want a label more than anything." She stated "I was trying not to get upset, cos I was trying to put into context how we felt it had all

happened”. Whereas Jane, who believed her son will be diagnosed with autism in the future, described “it was sadness I felt, I felt that I’d let him down.” Martha described difficulty with her memory during the assessment and worried that this had impacted on her responses. These examples demonstrate the pressure parents experience during the assessment and their subsequent feelings of doubt that the outcome was affected by their poor reporting.

**4. Unrelenting Battle:** Parenting a child with autistic characteristics and the journey of seeking diagnosis and support was described as a “huge battle”. Melissa stated “you’re continually fighting for services, fighting for support, fighting for a better life”. Parents used words such as “painful”, “exhausting”, “disheartening”, “a sinking feeling” and “like you’re walking through mud” to describe the emotional impact of their perceived battle of the assessment process. A major factor contributing to this perception was long waiting times and the involvement of multiple professionals. This was evident as some families reported that they had been “under services” for years. Additionally, using the word “under” suggests that services are viewed as powerful and further denotes the parents’ feelings of losing control.

I have waited long enough. It’s...he’s been battling this since he was about eight and erm...no (...) I’ve been battling it since he was about eight – Vicky.

There’s always a road block at the end of the road we go down so we just have to do U-turn (...) there are very long waiting lists to get seen, so if you do get knocked back and do try to do it again it’s another six months – Paul.

Vicky and Paul illustrated their frustration about long waiting lists and their use of the first person shows how the journey can be all encompassing for the whole family. Other parents

noted that being informed of long waiting times, albeit frustrating, helped to manage their expectations.

I'm angry now because I should have been stronger (...) I should have fought harder (...) one side of me was kind of saying right well, there's nothing wrong so that's good (...) the other side was like no this isn't right! – Emma.

Emma described that she “should” have fought harder, signifying an internal battle as if she did not do herself or her son justice. Another mother, Jane, emphasised the need to be strong and emotionally in control. She described mothers who were “fighting” for diagnosis as “Lions...they're strong women (...) y'know that overly dead sweet nurturing lioness thing, but y'know fiercely protective.”

Another aspect of the battle reported by parents was trying to gain public acceptance. Typical daily activities were described as a “challenge”. The lack of public awareness for autism and misinterpretation of the child's behaviours often resulted in criticism or “staring”. This was illustrated by Melissa, whose quote depicts her interpretation that continually fighting with services and being subjected to judgment in public led to personal self-growth. Consequently, she felt determined and “more confident” to tackle situations head on to protect her daughter.

I'm a lot more protective (...) if we're in Tesco and you know she's having a tantrum, which looks quite strange to most people at 13, erm and somebody will say something, I do sort of turn around (laughs). Whereas one time I would have bit my tongue and got upset...I was just a bit fed up of people being negative towards her – Melissa.

Many parents reflected that gaining a diagnosis might have changed this experience, giving the impression that diagnosis is a badge, which symbolises they have won the battle.

### **Understanding the Outcome**

**1. Lack of Closure:** In discussing assessment outcomes, many parents reflected on their perceived lack of closure and the associated mixed feelings.

It's like having a boat and somebody holding on to the rope and that's fine but then somebody lets the boat go, and your sort of going 'ok, now what we gonna do? (...) It's going to be like after until we get to a point where Oliver hmm is either diagnosed or I get him a statement for what he is, because he's not functioning in mainstream, but he hasn't got any particular label to peg on a board to make it easier – Jane.

Jane's metaphor described her trying to process her emotions after the assessment. She illustrated a sense that she believed the process was unfinished.

Some parents doubted the outcome as they thought that professionals had only observed a "snap shot" of the child or saw them on "a good day". In addition, conflicting opinions from health and education services and in some cases between same service professionals, led parents to feel confused and frustrated at the outcome.

His teachers have told me they can't understand why he hasn't been given a diagnosis because they can quite clearly see that there's something – Emma.

I don't understand how one person can say "yeah he's on the autistic spectrum" and somebody else can do a U-turn and say "we don't feel that he needs any help" – Vicky.

Their confusion was exacerbated by a lack of knowledge about how to access further support or explanation. One parent felt relieved they could access emergency appointments, whilst others felt like a "burden" or were too "angry" to re-contact the service.

It just feels like I've just had a locked door...and now I'm having to find this key, that is on a key chain with about a million keys on it...you know it's just been shut the door, lock it and that's it – Vicky.

Whilst Vicky's quote suggested her complete closure from the service, she lacked personal closure and felt she alone was still searching for an answer. Her quote also demonstrated a sense that she was set a test of commitment to locate the key to open the door. Consequently, she felt let down by the service.

I think you need to know that you're not excluded from the building, 'don't come here anymore with your er with your Munchausen by proxy saying your son's this and that and the other' cos that's not what I heard when I was in the room – Jane.

In many cases, parents recommended that the service should allow parents time to process the outcome before being invited to further discussions.

**2. Relief:** Many parents expressed relief that their child did not meet the criteria for a diagnosis. Parents who felt stronger relief were those whose child was referred following advice from professionals, rather than originally raising the concerns themselves.

Sarah acknowledged the enormity of her relief by stating the impact a diagnosis could have on her son's life. "It was a big relief! Because it's not just about school, it's about relationships and the rest of his life". Martha also expressed relief, but demonstrated some ambiguity in terms of questioning what the problem was if not autism. She also reflected on the importance of understanding her son's needs better, particularly as they worried that his difficulties may have been attributed to their "parenting".

A relief! And a bit of a shock! In one way, cos obviously he was showing a little bit of signs cos otherwise he wouldn't have been assessed in the first place, (...) it's a mixture of feeling relieved cos we know he hasn't got it, but then a bit shocked as well cos we were like well why is he the way he is? – Martha.

For other parents, relief was expressed as a fluid emotion that changed according to fluctuations in the child's presentation. For example, Emma stated "initially I was relieved" as her son exhibited improvements. However as these were short lived, her journey to fight for a diagnosis continued. Jane who also continued to seek a diagnosis explained that "it wasn't easy to hear 'no', but it was easier than hearing yes". She appeared to be relieved that despite her own concerns, she was pleased a diagnosis was not confirmed.

**3. The Future:** When summarising the assessment process, all parents reflected on their future hopes and worries. Some parents expressed concerns regarding education and their child's ability to independently manage the demands of adulthood.

If she doesn't get an education and she doesn't get the social support then what's she going to do, what job is she going to have and what life is she going to have? – Melissa.

Many parents spoke of the value that gaining a diagnosis would have provided in terms of gaining educational or therapeutic support, understanding and acceptance.

If I've got that little piece of paper, just that little piece of paper, that just says what's going on, give him a break, give him a chance – Emma.

Emma's use of the phrase "that little piece of paper", also used by two other parents, minimised the impact of diagnosis to just being words on paper. Ultimately, they felt that their child's difficulties could be explained by an autism diagnosis, but worried that without this validation they would not receive the necessary support. For some parents this meant their child was unlikely to fulfill their potential, whilst others expressed concerns about their child's well-being and mental health. Parents who worried less about the future felt that the assessment offered a deeper understanding of their child and were pleased that they could now focus on moving forward.

Despite the difficulties parents reported in navigating this process, many highlighted positive aspects of their experience. They described it as "sensitively managed", professionals as "skilled", "friendly" and that they "helped us understand" by highlighting the child's strengths rather than focusing on their difficulties.

## **Discussion**



This research explored parents' experiences of the ASD assessment process when no diagnosis was given. The themes illustrated issues encountered by parents in describing their child's difficulties without a valid explanation, yet celebrated these differences in shaping their child's personality and parents' resilience. Parents also described the emotional and psychological impact of the process. They reflected on the support received and the battle they engaged in to gain acknowledgment and acceptance from services and the public. Receiving the assessment outcome triggered a range of emotions. Some parents felt relieved and positive about the future, whilst others felt frustrated, questioning the validity of the assessment and determined to seek a second opinion. Despite the difficulties raised, some parents described the process as a journey. They reflected on the challenges along with positive aspects of the assessment and their own self-growth as a parent and an individual.

To the authors' knowledge, this research was the first of its kind. Nevertheless, like the parents whose child *was* diagnosed with ASD in Goin-Kochel et al., (2006) and Watson et al., (2011), many parents were dissatisfied with long waiting times. However, parents who expected this wait, usually having been informed by friends or support groups, rather than the service itself, were more accepting and reported that knowing a timeframe was useful. One parent whose child was seen urgently, reflected positively. She explained that knowing the outcome quickly enabled them to move forward rather than "it hanging over your head".

Many parents described feeling "paranoid" that professionals would not believe or validate their concerns. Whilst two parents felt professionals did not listen or attend to their child's needs, others experienced this fear to be unfounded. They reported that professionals were "friendly", "listened" and "asked the right questions" to elicit important information. One parent described that being informed of their child's strengths and weaknesses in relation to why the diagnosis was not made, improved her understanding and empowered her to seek educational support. Although mixed experiences were reported, to some extent this

contradicts the experience of parents who received a diagnosis in the Crane et al., (2016) study, who felt ignored or were re-referred to another professional.

Like Midence and O'Neill's (1999) findings, most parents expressed relief at the outcome. The manifestation of relief differed between parents, but was predominantly attributed to 'knowing' the outcome. In their study, confirmation of the diagnosis provided relief as parents could work towards acceptance. However, in this research, although some parents were relieved not to receive a diagnosis, for others hearing that ASD symptoms were evident, despite not meeting the full diagnostic criteria, mitigated their perceived judgement or strengthened their fight for further assessment. Without the diagnosis many felt they could not access support, a finding consistent with Keenan et al., (2010).

### **Clinical Implications**

Given the emotional and psychological challenges parents encountered, important clinical implications are raised. The difficulties reported by many parents predominantly related to issues before and after the assessment. For example, during the long wait parents felt alone and apprehensive. Following the assessment, although many felt relieved, some were confused, lacked closure and were concerned about the future.

Providing information at the point of referral about waiting times, the assessment process and advice to record information prior to the assessment, could alleviate parents' apprehension. Adopting a similar model to the one used in dementia services, where pre and post assessment counselling is offered, might also provide the associated benefits of parents' engagement with services and better adjustment to outcomes (La Fontaine, Buckell, Knibbs & Palfrey, 2014). In autism services, this counselling could enhance the parent-child-professional relationship and reduce their perception of the process as a battle. During pre-assessment counselling, parents' concerns, their reasons for seeking diagnosis and expectations can be

discussed. This meeting would establish rapport, allow the professional to tailor the assessment and manage parents' expectations. Offering post-assessment counselling, regardless of the outcome, would be beneficial to explore the impact and outcome of the assessment and henceforth reduce re-referral rates.

A child not being given a lifelong diagnosis is positive. However, many parents believed that a diagnosis was essential to receive support and were therefore disappointed and worried about the future. To challenge this perception, services should focus on developing a formulation to inform the families understanding of why the diagnostic criteria was not met. Sharing this formulation will educate other professionals involved and enhance collaborative working, knowledge and acceptance of neurodiversity and allow for a needs-based management plan.

Whilst implementing a more thorough assessment process is ideal to overcome some of the difficulties reported, the demand on services and current waiting times must be considered. Therefore, where appropriate, signposting to support groups or voluntary organisations may be beneficial.

In addition to service developments, the interpersonal, therapeutic and diagnostic skills of the professional are important. Many parents felt powerless, "paranoid" and described the overwhelming emotional impact of the assessment. Therefore, professionals must have the appropriate skills, knowledge and attitude to conduct the assessment and provide sensitive feedback. Training should be offered for non-diagnosis delivery along with time to reflect on the impact of this during clinical supervision.

Ultimately, improving families' experience of the assessment process may facilitate better parent-professional relationships and acceptance of the outcome. However, whilst it is important to consider areas of improvement to ensure best practice, positive aspects were highlighted, which should be recognised as areas of strength for future benchmarking.

### **Limitations and Future Research**

A number of limitations are considered. Firstly, the cross sectional design meant parents' experiences were only explored at one time point. Many parents reflected on the time they needed to process the outcome, suggesting that their feelings and reflections may change over time. Therefore, future research should utilise longitudinal methodologies to ascertain whether the opportunity for further processing time would alter the parents' perceptions. Additionally, some parents who were not completely satisfied with the outcome were keen to seek further assessment. A follow-up study to see whether professionals had reached the correct outcome or whether a diagnosis was provided at a later date and parents' experience of this would be useful.

Secondly, recruitment difficulties meant that only six interviews were conducted. Furthermore, all participants were from North East Wales and one neurodevelopmental team. According to the responses of interviewed parents, recruitment difficulties may relate to: 1) limited time as parents attend multiple appointments; 2) difficulties arranging childcare for children with autistic characteristics; 3) avoidance of discussing the assessment due to the emotional impact. These factors should be considered for future recruitment. Future research may benefit from the inclusion of additional socio-demographic data, in particular the cultural identity of the participating families as this was not collected in the current study. Additionally, looking at the experience of male carers would be useful as only one step-father was recruited.

Thirdly, the interviews were conducted in the clinic where the child was assessed and by the first author who worked in the neurodevelopmental team that carried out the assessment. This may have inhibited some parents to share certain experiences.

This study was the first, to the authors' knowledge, to explore parents' experiences when a diagnosis is not given. However, exploring the experiences of professionals who make

the decision and feedback a non-diagnosis is recommended. This would further improve our understanding of this complicated area.

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Contributions to Theory and Clinical Practice

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## **Introduction**

This research examined parents' perceptions of Autism Spectrum Disorder (ASD) and the assessment process. The literature review explored parents' beliefs about the cause and course of ASD, whilst the empirical paper provided a detailed insight into parents' ASD assessment experiences when a diagnosis was not given. The current paper will consider the mutual contribution of these findings and will be presented as follows: 1) theoretical implications and recommendations for future research, 2) clinical implications, and 3) personal reflections.

### **Theoretical Implications and Future Research**

The two areas studied: parents' perceptions about ASD and assessment experiences when a diagnosis was not given, have thus far been neglected in research and clinical practice. Previous research has focused on scientific explanations about the possible causes of ASD, whilst research into parents' assessment experiences has predominantly been explored with families who received a diagnosis. However, the current findings highlight the importance of understanding parents' etiological beliefs and assessment experiences, regardless of the outcome.

A theoretical model which can be applied, and facilitate our understanding of the current findings is the Health Belief Model (HBM; Rosenstock, 1974). Consistent with the literature review, the model asserts that socio-demographic variables such as age, income and education along with a person's beliefs about diagnosis, will influence health-related behaviours. Whilst the model was originally created to explore individuals' perceptions of their own health, it was later used to understand parents' health-behaviours (Bates, Fitzgerald & Wolinsky, 1994). The model includes four main components: perceived threat, benefits, barriers and self-efficacy. It can be applied to the context of parenting a child with autism or

undergoing the assessment process, as each component is thought to influence the parents' beliefs and in turn their health-care decisions (Wildman, 2006). The model has also been used to understand parents' satisfaction with the ASD assessment process (Saggu, 2015).

The first component, 'perceived threat' applies to the empirical paper. Parents considered areas of their child's life which could be under threat: education, well-being and future aspirations. More systemic factors posing a threat were lengthy waiting times, "paranoia" that professionals would not validate their concerns and their perceived lack of access to support or public acceptance without a valid label.

The second and third components, 'perceived benefits and barriers' relates to how parents' beliefs about the course of ASD and the efficacy of potential treatments may vary (Wildman, 2006). Consistently, the literature review evidenced that parents' etiological beliefs were associated with treatment decisions. For example, a study conducted in the USA found that parents who believed autism was a gift were less likely to seek professional advice or intervention (Jegatheesan, Fowler & Miller, 2010). Additionally, cultural influences and societal judgement also impacted on health beliefs, as families living in communities such as those on the Kenyan Coast, who regarded autism as a bad omen predominantly focused on the perceived benefits of treatment, hoping for a cure (Gona et al., 2015). This component can also explain wider healthcare decisions. For example, if parents believed immunisations caused their child's autism, they were more inclined to amend their vaccination schedules (Bazzano, Zeldin, Schuster, Barrett & Lehrer, 2012). Their tendency to use complimentary and alternative medicine (CAM) which can be expensive and lack scientific evidence, indicated their ongoing mistrust of medical interventions. Moreover, Saggu (2015) who assessed the 'perceived benefit' component of the HBM in relation to parents' assessment satisfaction found that affluent parents, who accessed private and timely assessment facilities, were more satisfied. This finding was largely related to the time that practitioners invested in explaining the

outcome along with the implications of post-assessment support. In order to safeguard against non-evidence-based decisions, professionals have a duty to ensure parents are informed of the benefits and barriers to diagnosis and intervention. Investing time to guide parents through the diagnostic process and intervention options, facilitates the final component of the model, self-efficacy. This refers to parents' belief in their own ability to support their child (Wildman, 2006; Saggu 2015). Conclusively, using the HBM as a psychological framework has multiple benefits. It allows professionals to gain a deeper understanding of parents' beliefs and plan needs-based support accordingly, which as stated in the literature review, parents are more likely to accept (Gona et al., 2015).

A further theoretical framework important to the current findings is the attribution theory (Weiner, 1985). This explains how individuals make sense of stressful events based on three causal dimensions. 1) *Locus* (whether the cause of an event is perceived to be internal or external); 2) *Stability* (the perceived likelihood that the event will change over time); and 3) *Controllability* (whether the event can be altered by the individual or is restricted to external factors). Previous research found significant associations between controllability and maternal affect (Dale, Jahoa & Knott, 2006) and that attributions are associated with parental adjustment to an ASD diagnosis (Mickelson, Wroble & Haldeson, 1999). A number of plausible links can be made between the current findings and the dimensions detailed within the theory.

Regarding the locus of cause, many studies in the literature review highlighted the impact of internal versus external attributions. For example, parents in Jordan who attributed the etiology of autism to internal factors, such as genetics or carelessness during pregnancy experienced guilt about the diagnosis (Al-Dababneh, Al-Zboon & Baibers, 2016). Furthermore, Chen et al., (2015) whose sample of Taiwanese parents predominantly endorsed an internal cause (genetics), found that 38.5% vetoed further pregnancies due to the risk of having another child with ASD before consulting with medical professionals regarding their

reoccurrence risk. In another study conducted in the USA, parents who endorsed genetics and blamed themselves, were less critical of their child as they perceived the diagnosis to be beyond the child's control (Wasserman, Weisman de Mamani & Mundy, 2010). Parents perception about the locus of cause can also influence their healthcare decisions. For example, studies that highlighted external causal factors, such as toxicity (Bazzano et al., 2012), found that parents were more likely to employ protective strategies, such as altering vaccination schedules.

The dimension of stability, could explain the research theme 'the future'. In the case of not receiving a diagnosis, parents may view the situation as stable because without a diagnosis they feel unable to access appropriate intervention, and thus the child's symptoms will remain unchanged. Consequently, lowering expectations and increasing worries about the future. Alternatively, they might perceive not having a diagnosis as unstable as they consider the future to be unpredictable, particularly if they continue to fight for a diagnosis. As found in the literature review, parents' perception of stability can be associated with their socio-demographic status (Zuckerman, Lindly, Sinche & Nicolaidis, 2015). For example, in receiving a diagnosis, parents of Caucasian compared to Hispanic children, were more likely to endorse the belief that autism is lifelong.

The third dimension, controllability, also relates to the empirical themes. Specifically, parents reflected on the element of control in the theme 'impact on self' and 'unrelenting battle'. Parents who described feelings of losing control, or that services held the power to affect positive change for their child (external attributions of control) also reported feeling "helpless". Parents perceived they "should have fought harder" to gain recognition for their child's difficulties. Alternatively, one mother who believed she could help her child, through advocacy or teaching social and educational skills (internal controllability) was accepting of the outcome, despite her hope for a formal diagnosis. This finding is important, particularly when no diagnosis is given, because if professionals promote parent-directed interventions, it

may reduce parental helplessness and enhance their acceptance of the outcome. Whilst, these links highlight the importance of recognising parents' attributions, further exploration is warranted. This would facilitate a better understanding of their beliefs, experiences and decision-making relevant to ASD.

The literature review indicated numerous factors which affect parental beliefs. These included, new cultural influences (Ravindran & Myers, 2012), the media (Chen et al., 2015) and perceived intervention success (Alqahtani, 2012). However, as these studies were cross-sectional, longitudinal research is warranted. Moreover, psychological models such as the five-stage model of grief (Kubler-Ross, 1970) and the cognitive adaptation model (Taylor, 1983) propose that parents are likely to experience several 'stages' before accepting or adjusting to their child's diagnosis. Therefore, exploring time since diagnosis in relation to parental beliefs and to understand their post-assessment reaction is crucial. For example, the Kubler-Ross (1970) grief model, which consists of five stages "denial, anger, bargaining, depression and acceptance" (Watson, Hayes & Radford-Paz, 2011, pg. 47) was first related to parents of children with ASD by Huber (1979). Huber described that upon first noticing differences in their child's development compared to their peers, parents typically make excuses for atypical development (*denial*). As they process the realisation that their child is different, they enter the *anger* phase. Parents blame themselves, each other or project this towards external influences such as vaccines. *Bargaining* begins when parents seek professional advice in the hope of accessing support and intervention. Following this, they experience a sense of loss as they realise that they must accept the situation and uncertainties of the future, leading to a period of *depression*. During the *acceptance* phase, parents may be more open to considering multiple causes beyond their control or knowledge and for those who did not receive a diagnosis, relinquish the battle. Improved understanding about whether parents' beliefs or reactions to the assessment change according to their stage of acceptance is important. With this awareness

professionals could tailor advice regarding evidence-based interventions and be better informed about appropriate timeframes to offer a post-assessment consultation, as recommended in the empirical paper.

Ultimately both papers demonstrate the importance of professional's investing time with parents to develop a good rapport based on mutual respect, trust and openness. The empirical paper highlighted that some parents perceived they had to battle with professionals and services rather than work alongside them, whilst the literature review found that parents who felt that professionals had disregarded their views were dissatisfied with the process (Jegatheesan et al., 2010). However, further research regarding specific factors associated with positive parent-professional interactions would be useful to guide future communication.

Culture and socio-demographic variables were raised as important factors in the literature review as they are influential on parents' beliefs, interactions with professionals, treatment and family planning decisions. Although the review provided useful information, further questions remain and the following areas are recommended for future research, and especially to improve professional's cross-cultural awareness.

- Further exploration of the impact of private health insurance on parents' beliefs and assessment experiences, as this was only explored in brief by Zuckerman, Lindly and Sinche (2016).
- The perceptions of fathers and parents of girls, as they were consistently under-represented in both the literature review and the empirical paper. Whilst the inclusion of fewer girls reflects current prevalence rates (Lai, Lombardo, Auyeung, Chakrabarti & Baron-Cohen, 2015), symptoms often manifest differently in females, leading to later diagnosis (Begeer et al., 2013), and thus may influence parents' perceptions of the assessment process.



- Further insight into the direct impact of socio-demographic variables on parents' experience. For example, it would be useful to apply a mixed methods approach to explore the association between socio-demographic variables and factors such as assessment satisfaction, etiological beliefs or future expectations, whilst maintaining a qualitative component to understand their lived experience.

Finally, the aim of this research was to increase our understanding of assessment experiences when a diagnosis is not given and parents' etiological beliefs. Whilst this has to some extent been achieved, it also raised awareness of further areas of uncertainty. For example, although some of the empirical findings are consistent with the experiences of families who received a diagnosis, there has been no direct comparison between parents who do and do not receive a diagnosis from the same service. This would serve as a useful measure to identify whether perceptions differ according to the outcome. Similarly, as different services use different diagnostic methods, it is important to determine whether the assessment method impacts on parents' satisfaction and trust in the outcome. Furthermore, it would be useful to understand professionals' perceptions about the assessment process. Specifically, their perceived competency in engaging families to discuss their etiological beliefs and expectations, providing evidence-based information in line with these beliefs, and sharing a non-diagnosis. These insights would compliment the current findings, identify training and supervision needs and future contribute to standardised best practice protocols.

### **Clinical Implications**

The findings of both papers highlight important clinical implications, which aim to improve professional knowledge and practice within ASD teams and enhance the assessment experience for families and young people. To make recommendations for best practice based on the

findings, the current National Institute for Health and Clinical Excellence (NICE) guidelines for the recognition, referral and diagnosis of ASD in young people under the age of 19 (NICE, 2011) must be considered.

The NICE guidelines state that services should establish effective pathways for improved symptom recognition and referral, assessment should commence within three months of the referral and a case coordinator should be allocated. Furthermore, clinicians should possess the skills and competencies to conduct a thorough assessment, including an in-depth understanding of the families' concerns, and be able to sensitively feedback the outcome along with a needs-based management plan. If uncertainties arise, a period of watchful waiting or a second opinion should be considered. The guidelines also advocate for good patient-professional communication and the provision of evidenced-based information appropriate to families' needs and choices.

The current findings evidence examples of poor adherence to these recommendations along with important factors for inclusion in future guidelines. The relevant implications and recommendations for revisiting or updating the guidelines will be discussed using individual subheadings.

### *Professional Training*

The development of a strategic approach to professional training will improve clinical competence and compliance to guidelines, enhancing the delivery of high quality standardised assessments. To achieve this, autism specific modules should be incorporated into professionals' pre-qualification training. Furthermore, to address the issues detailed in the empirical theme 'understanding the outcome', a key element of such training should focus on the sensitive delivery of assessment outcomes. Medical professionals receive training in the breaking of bad news protocol, defined as delivering "any information that is not welcome"

(Arber & Gallagher, 2003). Based on this definition, bad news is dependent on the families hopes for the assessment outcome, which can be established during pre-assessment counselling and is relevant when a diagnosis is or is not given.

The literature review highlighted that a person's culture can influence their etiological views, treatment choices and their own well-being when caring for a child with autism (Al-Dababneh et al., 2016). Therefore, professionals must embrace a strong awareness of cultural diversity and the potential associated implications. Correspondingly, culture should be a component included in professionals training and reviewed regularly with families, as cultural influences are fluid and adapt according to new information (Ravindran & Myers, 2012). Correspondingly, NICE guidelines should be updated to stipulate that practitioners need to be cross-culturally competent.

In addition, ongoing opportunities for continuing professional development are essential for clinicians to remain aware of the latest evidence-based practice. The development of peer-supervision or expert reference groups could also be beneficial for ongoing skill development, complex case discussion, reflection, building a professional identity and the sharing of best practice locally (Newman, Nebbergall & Salmon, 2013).

The literature review revealed the long-lasting impact media can have on parents' perceptions, regardless of new claims. For example, following the vaccine-autism link, parents continue to believe vaccines caused their child's autism regardless of the claim being discredited (Bazzano et al., 2012). Therefore, a further necessary implication is the need for professionals to be aware of autism related media and counteract unfounded claims with evidence-based information. Additionally, researchers have a responsibility to present scientifically valid, robust and peer-reviewed findings.

Waiting times was one aspect which contributed to the parents' view of the process as an 'unrelenting battle'. In some cases, parents reported having waited over a year for

assessment, which exceeds the NICE recommendation and must be addressed. Autism Achieve Alliance (2014) found that receiving thorough information about the young person prior to assessment reduced waiting times. This finding suggests implications for the wider training of other professionals, such as GPs and education services in making comprehensive referrals.

### *Pre and Post Assessment Counselling*

Both papers advocate the need for comprehensive assessments and improved communication with parents to gain a deeper understanding of their concerns and perceptions of their child's difficulties. This could be addressed by considering pre and post assessment counselling, which as discussed within the empirical paper has been shown to be successful in dementia services (La Fontaine, Buckell, Knibbs & Palfrey, 2014). This is supported by the recent introduction of pre and post diagnostic counselling in adult ASD services across Wales (Betsi Cadwaladr University Health Board, 2012). However, there is currently no such provision for younger service users. Although services are under pressure to provide quicker assessments, it was concluded that gaining thorough pre-assessment information might expedite the process. In addition, pre and post assessment work could be provided by other team members, such as neurodevelopmental support workers or assistant psychologists, thus creating capacity for clinicians to provide assessments. Good team communication is necessary so that information is shared appropriately to inform the assessment and outcome.

During pre-assessment work the focus should be to obtain young peoples' and parents' concerns and beliefs about their difficulties. A possible diagnostic outcome, its advantages and disadvantages, as well as the absence of reaching a diagnosis should be discussed and information detailing the process and waiting times provided. By managing parents' expectations, we can alleviate pre-assessment anxiety, allowing parents to present their

concerns and formulate questions. Mockett, Khan and Theodosiou (2011) found that the provision of such pre-assessment information positively impacted on parental satisfaction.

During post-assessment work, the impact of the diagnosis or lack of diagnosis should be discussed. Regardless of the outcome, reference to the bio-psycho-social model (Engel, 1980) is important during this discussion in order to adhere to the NICE recommendations of developing a needs-based management plan. Therefore, rather than subscribing purely to the medical model of diagnosis, a formulation of the child's strengths and difficulties subsequent to the assessment is essential. This should be shared with relevant professionals and could contribute to the child's pupil profile to highlight that whilst a diagnosis was not given, the child presented with behaviours that warranted professional assessment.

Pre and post assessment discussions should focus on making the family equal partners in the process. As highlighted in the literature review, professionals should be culturally sensitive and aware of factors influencing parents' decisions, including their religious views, beliefs, socio-economic status and academic ability. Furthermore, specific consultation about their beliefs in relation to these factors are important, as they can impact on the parent-professional relationship, maternal well-being, decisions for treatment and future family planning. Regardless of whether a diagnosis is given, professionals should also enquire about current or intended treatment use, including CAM treatments, and provide evidence-based information where appropriate.

Post-assessment work could be informed by the principles of Acceptance and Commitment Therapy (ACT; Hayes & Lillis, 2012). This would help parents to manage the outcome and accept any associated uncertainty to enable them move forward and to manage worries about the future. Lastly, parents should be informed of alternative services along with the pathway to re-accessing support from the assessment service following discharge.

### *Needs-led Service Provision*

Services should be needs-led rather than diagnosis-led. Parents within the empirical research were ambivalent about their child not receiving a diagnosis. For some this was particularly challenging as they believed that without diagnosis, the child could not access appropriate support. This replicates findings from a recent document titled 'The autism diagnosis crisis' (National Autistic Society, NAS, n.d). The document highlights that without the correct support young people may develop mental health difficulties and consequently require additional support. Therefore, based on the recommendation for a formulation or needs-based plan, young people should be able to access services regardless of diagnosis.

### *Policy Development*

The empirical research highlighted that many parents experienced uncertainty in the outcome. Examples included the perceived lack of consistency between professional opinions, or acknowledgement that the child presented some symptoms that parents interpreted as confusing or would eventually lead to diagnosis. This was expressed through the themes 'lack of closure' and 'the future'. However, as previously mentioned, the NICE guidelines state that if there is any uncertainty subsequent to the assessment the child should be monitored or a second opinion sought. It is hoped that the other recommendations will improve assessment satisfaction, trust in the outcome and access to support regardless of diagnosis. However, a policy stating the appropriate pathways to seek a second opinion or reassessment is still required, and should be accessible to both professionals and parents as this is currently unclear within North Wales. This is particularly important as some parents in the empirical research were "too angry" or did not know who to contact with questions or concerns following the assessment outcome. Additionally, services should provide clear advice about the advantages

and disadvantages of accessing private centres to seek a second opinion and should be transparent about whether they will accept a private diagnosis.

### *Ongoing Audit and Evaluation*

A critical aspect of implementing service improvements, as documented within the NICE guidelines, is the need for ongoing audit and evaluation. The empirical findings advocate the need for service users and their families to be part of this process. Whilst this may need to be conducted on a smaller scale than the current research, due to time and resource restraints, continued investment is vital. This is supported by a recent document, 'The life we choose: shaping autism services in Wales' (NAS, 2011). This document recognises that without continued investment to improve services, families will continue to perceive the process as a 'battle', and their level of need will escalate, creating more pressure on costly services and interventions.

### **Personal Reflections**

Reflection is a fundamental component in interpretative phenomenological analysis (IPA) research and in general clinical practice. Keeping a reflective journal throughout the process promoted self-awareness by allowing me to track my thoughts and feelings about the research. This helped me to remain focused, identify knowledge gaps and celebrate moments of achievement which may otherwise have been taken for granted amidst the demanding research schedule. The journal was particularly invaluable during the analysis as IPA utilises the principle of double hermeneutics (the researcher interpreting the interpretations of the participant). Acknowledging my own thoughts and preconceptions minimised bias and enabled me to concentrate predominantly on the participants' experience.

During my current training and previous clinical work with families and in specialist autism services, I have become passionate about gaining a deeper understanding of the experiences of families affected by neurodevelopmental conditions. I hoped that this research would allow me to further my own understanding whilst highlighting two areas of autism, which are currently under-researched yet have great clinical importance if families are to receive highly quality care. I was however aware that as a result of this previous work and witnessing the challenges faced by families with children with autism, I believed that families who did not receive the lifelong diagnosis would react positively. Using supervision to explore this preconception was essential and enabled me to remain mindful of this during the interview and analytic process.

Whilst conducting the research, I also commenced a clinical placement within the recruiting Neurodevelopmental team. This was useful as it provided me with knowledge of the service and assessment protocols, which helped me to understand the parents' journey. Whilst this facilitated my rapport with some parents during the interviews, I was aware of the potential for a perceived power-imbalance and that this may have simultaneously limited parents' honesty in sharing all aspects of their experience. To overcome this, I explained my role to participants, the purpose of the research, and emphasising the importance of feedback and confidentiality reassured them that the level of care they receive would not be impacted upon. Another challenge arising from my dual role as team member and researcher was that colleagues were interested in the feedback of families who they had contacted to participate. Whilst they were aware of confidentiality, I wanted to avoid concerns about the findings being a critical reflection on them or the service. Therefore, I shared the aims of the research with the team and valued time with them to reflect on the benefits of receiving feedback.

Conducting this research was my first exposure to qualitative analysis. I was keen to utilise the opportunity to broaden my research skills and this method was well suited to the



research objective. However, given the enormity and the importance of the research, personally and for contribution to the body of knowledge, this initially caused apprehension. I was aware of the expectation to gather rich data and represent the mutual experiences of each participant, rather than finding one objective truth as I was used to in quantitative research. Initially, this uncertainty was anxiety-provoking, but as the interviews commenced I was eager to understand parents' journeys and develop themes which accurately encapsulated their experience.

Being genuinely interested in parents' experiences presented a challenge during preliminary interviews, as some parents predominantly described the process of their child's difficulties rather than their feelings about this. With the pressure to gain data that was rich enough, I initially felt disheartened when transcribing the interview, as I felt I had neglected opportunities to gain a deeper insight into their experience. However, reflecting on this, attending IPA training and liaising with other IPA researchers was invaluable as this reaffirmed the principles of IPA. I also learnt to use effective prompts to facilitate parents to reflect on their own interpretation of their experience. Another aspect I became aware of during transcription was how my feelings and interpretations altered slightly from the interview to listening back to the interview. In the interview, I built a rapport with parents and observed the non-verbal communication and emotions that accompanied their story. However, listening back to the interviews without these visual cues I connected more to the words rather than the individual. I remained mindful and reread my reflective journal several times during analysis.

A further consideration which arose during the interviews was the impact of parents' reactions. The interviews were highly emotive, however using the skills I have learnt throughout clinical training I felt able to manage difficult situations confidently. Yet, at times I felt the urge to adopt the therapeutic role I was used to. For example, wanting to validate parents' concerns yet challenge their self-critical beliefs or statements. Whilst this was frustrating, the awareness enabled me to focus on the researcher role and associated objectives.

One parent asked whether I was a mother myself. I wondered about the intention behind the question. Was it simply curiosity? Was it because she felt I had not responded in an empathic manner? Or was it perhaps because regardless of my response the fact that I am not a mother, or more specifically a mother to a child with autistic traits, she felt I could never truly comprehend her situation? After much consideration and reflection on this during supervision, I determined that the importance of my role as a researcher was not to be accepted by parents through sharing their experience, but to represent their experiences in order to support service development.

Another important reflection was the impact of hearing examples of substandard treatment, such as parents having waited years for assessments or perceiving the process as a battle. I felt disappointed for both the parent and for my colleagues who work exceptionally hard to provide a quality and timely service.

The analysis phase was both challenging and rewarding. As previously mentioned I was aware of my thoughts, feelings and of how my time working within the team could potentially influence my interpretation of the findings. This awareness along with the need to remain close to the data initially prevented me from having the courage to make meaningful interpretations, as I did not want to lose essence of what each individual was saying. Particularly during the cross-case analysis phase I noticed I was quite rigid in not wanting to abandon certain themes. However, to ease this process I adopted a creative approach by displaying potential themes on strips of coloured paper across a large storyboard. This approach afforded me the flexibility to review and change the themes until I felt satisfied that the chosen themes best reflected participants' stories. Although I was anxious about my final commitment to these themes, I was excited to have completed this phase of the analysis, as I was one step closer to representing their story and hopefully making meaningful contributions to clinical practice.

I was acutely aware of the value of qualitative research in the importance of each person's experience, unlike quantitative research whereby the individual simply becomes a number in a dataset. Consequently, I developed a strong attachment to parents' quotes and wanted to include everything they said. Whilst I appreciated the need to summarise the findings concisely, I found it difficult to decipher which quotes best illustrated the chosen themes. Incorporating reflection time and reconsidering the quotes at later date provided clarity and affirmed my interpretations of the findings and their clinical implications. However, I reflected upon how participants would feel if they were to read the quotes I had selected and whether they felt I had done them justice.

As the research came to an end and I wrote about the implications derived from both papers, I reflected on the huge sense of accomplishment. As someone who has previously questioned my own research ability, I was struck not only by the skills I had gained but how much I had enjoyed the challenge of the process. This, along with my passion to further contribute to improved service provision for both families and professionals, has fuelled my desire to continue this research journey as I transition into my role as a Clinical Psychologist.

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## Appendices

**Appendix A**

**Health and Care Wales Research Ethics Committee Application Form**

## Appendix B

### Health and Care Wales Research Ethics Committee Provision Approval



#### Gwasanaeth Moeseg Ymchwil Research Ethics Service

Pwyllgor Moeseg Ymchwil Cymru 5  
Wales Research Ethics Committee 5  
Bangor  
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21<sup>st</sup> May 2016

Miss Lesley-Anne Bendik Trainee Clinical Psychologist  
North Wales Clinical Psychology Programme School of Psychology  
Bangor University, Bangor, Gwynedd  
LL57 2DG [psp511@bangor.ac.uk](mailto:psp511@bangor.ac.uk)

Dear Miss Bendik,

Study title: Parents experiences of the Autistic Spectrum Disorder assessment process when the child did not receive a diagnosis. REC reference: 16/WA/0164 Protocol number: Bangor university: 1568 IRAS project ID: 201170

The Research Ethics Committee reviewed the above application at the meeting held on 19 May 2016.

Provisional opinion: The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below. Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair. Further information or clarification required

#### In the Protocol

1. The protocol should include information on the process in place to handle incidental disclosures of abuse/malpractice.
2. The Committee requested that the opt-out process is changed to opt-in and participants should be asked to complete the form or confirm in an email, by telephone or by post, that they are willing to be approached by the researcher to discuss their potential participation in the research project.

#### In the Participant Information Sheet and Consent Form

1. The letter of Invitation to Participants should be amended to reflect the opt-in process as described above.

2. The Information Sheet should explain how incidental disclosures of abuse or malpractice will be handled, and explicit consent should be sought to breach confidentiality to action those disclosures which do not carry a Statutory Duty to report.
3. The paragraph “What are the possible benefits of taking part” should identify a direct benefit to the participant aside from the £10 remuneration. If no direct benefit can be identified, the paragraph should clarify that there are no direct benefits to the participant.
4. The paragraph “What will happen if I do not want to carry on with the study?” should also clarify whether the £10 remuneration will still be paid if the participant withdraws.
5. In paragraph “What is the purpose of the study?” the wording “young person has been given a positive diagnosis”, should be replaced with “a diagnosis of ASD”

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact Dr Rossela Roberts, RES Manager, using the contact details in the letterhead.

When submitting a response to the Committee, the requested information should be electronically submitted from IRAS. A step-by-step guide on submitting your response to the REC provisional opinion is available on the HRA website using the following link: <http://www.hra.nhs.uk/nhs-research-ethics-committee-rec-submitting-response-provisional-opinion/>

Please submit revised documentation where appropriate underlining or otherwise highlighting the changes which have been made and giving revised version numbers and dates. You do not have to make any changes to the REC application form unless you have been specifically requested to do so by the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 20 June 2016.

Summary of the discussion at the meeting

Ethical issues raised by the Committee:

Care and protection of research participants; respect for participants’ welfare and dignity; data protection and confidentiality

The Committee discussed the respect for potential and enrolled research participants’ welfare & dignity, the arrangements made to protect privacy through confidentiality and raised no issues.

*Data protection & research participant’s confidentiality*

The information governance aspects of the study were discussed, where and for how long will data be stored, and clarified who will have access to the data.

The Committee concluded that the information about subjects will be appropriately handled, but requested that the protocol includes information on the process in place to handle incidental disclosures of abuse/malpractice, as per the Bangor University Policy / Procedure.

*Redress*

The Insurance and indemnity (negligent/ non-negligent harm) mechanism has been clarified and compensation arrangements are in place

*Trial Registration*

The Committee noted that the study will be registered on the Bangor University repository.

**Informed Consent process and the adequacy and completeness of participant information**

The Committee discussed the provision of information to research participants about the purpose of the research, its procedures, potential risks, benefits, and alternatives, and whether it includes all procedures as described in the protocol.

The Committee noted that written informed consent is taken as part of a process - with participants having adequate time to consider the information, and opportunity to ask questions. The language used is understandable to the research participants, the information is clear as to what the participant consents to, and there is no inducement or coercion.

However, it was noted that participants are approached by the clinician (either in person or in correspondence) and they are required to complete an opt-out form if they do not wish to be contacted by the researcher with a view to be invited to take part in the research project;

The Committee requested that the opt-out process is changed to opt-in and participants should be asked to complete the form or confirm or in an email, by telephone or by post that they are willing to be approached by the researcher to discuss their potential participation in the research project.

The Committee agreed that the procedures described in the protocol have been adequately addressed in the Information Sheet, but felt that minor amendments should be made to ensure that individuals understand the information and can make a voluntary informed decision to enrol and continue to participate.

Information should be given on how incidental disclosures of abuse or malpractice will be handled, and explicit consent should be sought to breach confidentiality to act on those disclosures which do not carry a Statutory Duty to report.

The paragraph "What are the possible benefits of taking part" should identify a direct benefit to the participant aside from the £10 remuneration. If no direct benefit can be identified, the paragraph should clarify that there are no direct benefits to the participant.

The paragraph "What will happen if I do not want to carry on with the study?" should also clarify whether the £10 remuneration will still be paid if the participant withdraws.

In paragraph "What is the purpose of the study?" the wording "young person has been given a positive diagnosis", albeit technically correct, may imply to a lay person that this is the best outcome. The Committee requested that this is replaced with "a diagnosis of ASD"

**Other ethical issues were raised and resolved in preliminary discussion**

**Based on the information provided, the Committee was satisfied with the following aspects of the research:**

- Social or scientific value; scientific design and conduct of the study
- Recruitment arrangements and access to health information, and fair participant selection
- Favourable risk benefit ratio; anticipated benefit/risks for research participants
- Informed consent process Suitability of the applicant and supporting staff
- Independent review
- Suitability of supporting information
- Other general issues
- Suitability of the summary of the research

**The Committee identified issues with the following aspects of the research:**

- Care and protection of research participants; respect for participants' welfare and dignity
- The adequacy and completeness of participant information

**Documents reviewed**

**The documents reviewed at the meeting were:**

<i>Document</i>	<i>Versio</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor Insurance or indemnity (non-NHS sponsor only)]	1	20 July 2015
Interview schedules or topic guides for participants [Interview schedules or topic guides for participants]	1	04 May 2016
IRAS Checklist XML [Checklist_12052016]		12 May
Letters of invitation to participant [Letters of invitation to participant]	1	04 May
Other [Other (Opt-Out Form)]	1	04 May
Other [Other (Telephone Protocol)]	1	04 May
Participant consent form [Participant consent form]	1	04 May
Participant information sheet (PIS) [Participant Information Sheet]	1	04 May
REC Application Form [REC_Form_12052016]		12 May
Research protocol or project proposal [Research Protocol or project]	1	04 May
Summary CV for Chief Investigator (CI) [Summary CV for Chief]	1	04 May
Summary CV for supervisor (student research) [Summary CV for supervisor (student research)]	1	04 May 2016

**Membership of the Committee**

The members of the Committee who were present at the meeting are listed on the attached sheet No declarations of interest were made in relation to this application.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**16/WA/0164**

**Please quote this number on all correspondence**

**Yours sincerely**




**Dr Jason Walker, MB BCh BAO, FRCA Vice-Chair**

**E-mail: [rossela.roberts@wales.nhs.uk](mailto:rossela.roberts@wales.nhs.uk)**

*Enclosure: List of names and professions of members who were present at the meeting and those who submitted written comments.*

**Copy to: Sponsor:** **Mr Hefin Francis**  
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**Wales Research Ethics Committee 5 Attendance at Committee meeting on 19 May 2016**

**Committee Members in attendance**

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>	<i>Present</i>
Dr Karen BE Addy	Clinical Psychologist	Expert	Yes
Dr Swapna Alexander	Consultant Physician	Expert	Yes
Mrs Kathryn Chester	Research Nurse	Expert	No
Ms Geraldine Jenson	Retired College Vice-Principal	Lay +	No
Mr Eliezer Lichtenstein	Student	Lay +	Yes
Dr Mark G Lord	Consultant Pathologist	Expert	No
Dr Pamela A Martin-Forbes	WCRW Research Officer	Expert	Yes
Dr Paul G Mullins	Reader, MRI Physicist	Lay +	No
Mr VishwanathPuranik	Associate Specialist ENT Surgeon	Expert	Yes
Mrs Lynn C Roberts	Matron, Emergency Department	Expert	No
Dr Judith L Roberts	Research Officer	Expert	Yes
Mrs Rachel L Roberts-Jones	Student	Lay +	Yes
Dr Jason D Walker	Consultant Anaesthetist (Vice-Chairman, in the Chair)	Expert	Yes
Dr Philip W White	General Practitioner (Chairman)	Expert	No
Ms Sydna A Williams	Lecturer	Lay +	Yes

Dr Rossela Roberts	Clinical Governance Officer / RES Manager
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## **Appendix B (continued)**

### **Amendments: Researcher Response to the Researcher Health and Care Wales Research Ethics Committee**

Response to request for further information (New Document)  
 09/06/2016  
 IRAS ID: 201170 - Ref: 16/WA/0164  
 Bangor University Ethics Application Number: 15685  
 Experiences of the ASD Assessment when a diagnosis is not received

#### **Response to request for further information**

Thank you for your recent letter regarding my research ethics application. I have addressed all of the amendments detailed in your letter and have provided a summary of these below. These amendments can also be viewed as 'tracked changes' in new versions of the supporting documents, as requested in your letter.

#### Research Protocol or Project Proposal v2:

- The opt-out process has been changed to an opt-in process.
- Information on the process to handle incidental disclosures of abuse/malpractice has been included.
- Clarification that the participant will still receive the £10 voucher regardless of whether they withdraw from the study has been included.

#### Participant Information Sheet (PIS) v2:

- The wording "young person has been given a positive diagnosis" has been replaced with "a diagnosis of ASD".
- The opt-out process has been changed to an opt-in process.
- Information on the process to handle incidental disclosures of abuse/malpractice has been included.
- Clarification that the participant will still receive the £10 voucher regardless of whether they withdraw from the study has been included.
- Information that the participant will receive no direct benefits from participating in the study is stated.

#### Participant Consent Form v2

- Explicit consent to breach confidentiality in the event that disclosures of abuse or malpractice are made has been included.

#### Letters of Invitation to participant v2

- The opt-out process has been changed to an opt-in process.

#### Opt-in Form (New Document)

- The opt-out form has been replaced by an opt-in form, which details that individuals can opt-in to being contacted by the researcher to discuss their potential participation by post, email or telephone.

I hope these amendments are satisfactory. Upon confirmation of the decision, if the amendments are satisfactory, all tracked changes will be accepted prior to printing.

Yours Sincerely,  
 Ms Lesley-Anne Bendik (Principal Researcher).



## Appendix B (continued)

### Health and Care Wales Research Ethics Committee Final Approval



Gwasanaeth Moeseg Ymchwil  
Research Ethics Service



#### Pwyllgor Moeseg Ymchwil Cymru 5 Wales Research Ethics Committee 5 Bangor

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LL57 2PW

Telephone/ Facsimile: 01248 - 384.877

Email: [Rossela.Roberts@wales.nhs.uk](mailto:Rossela.Roberts@wales.nhs.uk)

Website : [www.nres.nhs.uk](http://www.nres.nhs.uk)

19 June 2016

Miss Lesley-Anne Bendik Trainee  
Clinical Psychologist  
North Wales Clinical Psychology Programme School of  
Psychology  
Bangor University,  
Bangor, Gwynedd  
LL57 2DG  
[psp511@bangor.ac.uk](mailto:psp511@bangor.ac.uk)

Dear Miss Bendik,

**Study title:** Parents experiences of the Autistic Spectrum Disorder assessment process when the child did not receive a diagnosis.  
**REC reference:** 16/WA/0164  
**Protocol number:** Bangor university: 1568  
**IRAS project ID:** 201170

Thank you for your letter of 13 June 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Dr Rossela Roberts, [rossela.roberts@wales.nhs.uk](mailto:rossela.roberts@wales.nhs.uk).

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

#### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion").

## Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Versi</i>	<i>Date</i>
REC Application Form [REC_Form_12052016]	-	12 May 2016
Other [Response for request for further information]	1	09 June 2016
Research protocol or project proposal	2	09 June 2016
Letters of invitation to participant	2	09 June 2016
Other [Opt in form]	1	09 June 2016
Participant information sheet	2	09 June 2016
Participant consent form	2	09 June 2016
Other [Telephone Protocol]	1	04 May 2016
Interview schedules or topic guides for participants	1	04 May 2016
Summary CV for Chief Investigator	1	04 May 2016
Summary CV for supervisor	1	04 May 2016
Evidence of Sponsor insurance or indemnity	-	20 July 2015

## Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

## After ethical review

### Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

## User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/WA/0164

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.  
Yours sincerely




**Dr Philip Wayman White,**  
**MBChB, MRSM Chair**  
E-mail: [rossela.roberts@wales.nhs.uk](mailto:rossela.roberts@wales.nhs.uk)

Enclosure: "After ethical review – guidance for researchers"

Copy to:

Sponsor:

Mr Hefin Francis  
School of Psychology  
Adeilad Brigantia,  
Penrallt Road  
Bangor  
LL572AS  
[h.francis@bangor.ac.uk](mailto:h.francis@bangor.ac.uk)

Academic Supervisor:

Dr Freya Spicer-White  
Clinical Psychologist  
Child Health Psychology  
Service Children's  
Outpatients Department  
Clan Clwyd Hospital,  
Rhyl Denbighshire  
LL18 5UJ  
[Freya.Spicer-White@wales.nhs.uk](mailto:Freya.Spicer-White@wales.nhs.uk)

R&D Office:

Miss Debra Slater  
Clinical Academic Office  
Ysbyty Gwynedd  
Bangor  
LL57-2PW  
[Debra.Slater@wales.nhs.uk](mailto:Debra.Slater@wales.nhs.uk)

## Appendix C

### Bangor University School of Psychology Ethics Committee Email Approval

Ethical approval granted for 2016615685 Parents Experiences of the Autistic Spectrum Disorder Assessment Process when the Diagnosis is Negative.

ethics@bangor.ac.uk  
Mon 04/04/2016 10:06

To: Lesley-Anne Bendik <psp511@bangor.ac.uk>;

Dear Lesley-Anne,

2016615685 Parents Experiences of the Autistic Spectrum Disorder Assessment Process when the Diagnosis is Negative.

Your research proposal number 2016615685 has been reviewed by the Psychology 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.

<https://outlook.office.com/owa/?viewmodel=ReadMessageItem&...%2F0mAAFyxDFAAA%3D&IsPrintView=1&wid=13&ispopout=1&path=>

## Appendix D

### Betsi Cadwaladr University Health Board Research and Development Committee Approval



Panel Arolygu Mewnol Y&D  
R&D Internal Review Panel  
Betsi Cadwaladr University Health Board  
Ysbyty Gwynedd  
Clinical Academic Office Bangor,  
Gwynedd  
LL57 2PW

Chairman/Cadeirydd – Dr Nefyn Williams PhD, FRCGP  
Email: [rossela.roberts@wales.nhs.uk](mailto:rossela.roberts@wales.nhs.uk)  
[debra.slater@wales.nhs.uk](mailto:debra.slater@wales.nhs.uk)  
[sion.lewis@wales.nhs.uk](mailto:sion.lewis@wales.nhs.uk)  
Tel/Fax: 01248 384 877

Miss Lesley-Anne Bendik  
North Wales Clinical Psychology Programme School of Psychology  
Bangor University Bangor  
LL572DG  
[psp511@bangor.ac.uk](mailto:psp511@bangor.ac.uk)

Dear Miss Lesley-Anne Bendik

**Re: Confirmation that R&D governance checks are complete / R&D approval granted**

**Study Title** Experiences of the ASD Assessment when a diagnosis is not received

**IRAS reference** 201170

**REC Reference** 16/WA/0164

The above research project was reviewed at the meeting of the BCUHB R&D Internal Review Panel

Thank you for responding to the Panel's request for further information. The R&D office considered the response on behalf of the Panel and is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

The Internal Review Panel is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board sites as described in the application.

The documents reviewed and approved are listed below

Document:	Version:	Date:
R&D Form	V5.3.1	14/07/2016
SSI Form	V5.3.1	14/07/2016
Protocol	V2	09/06/2016
Information sheet	V2	09/06/2016
Consent Form	V2	09/06/2016
OPT-in form	V1	09/06/2016
Invitation letter	V2	09/06/2016
Telephone protocol	V1	04/05/2016
Interview guide	V1	04/05/2016

Summary CV: Bendik		04/05/2016
Summary CV: Spicer-White		04/05/2016
Evidence of Insurance (UMAL)		Expires 31/07/2017
Risk Assessment		26/07/2016
REC favourable opinion letter		19/06/2016

The study should not commence until the Ethics Committee reviewing the research has confirmed final approval ('favourable opinion').

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009). An electronic link to this document is provided on the BCUHB R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If your study is adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that the Chief Investigator will be required to regularly upload recruitment data onto the portfolio database. To apply for adoption onto the NISCHR CRP, please go to: <http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979>. Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found at: <http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571> and/or from your NHS R&D office colleagues.

To upload recruitment data, please follow this link: [http://www.crncc.nihr.ac.uk/about\\_us/processes/portfolio/p\\_recruitment](http://www.crncc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment). Uploading recruitment data will enable NISCHR to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office.

If you need any support in uploading this data, please contact [debra.slater@wales.nhs.uk](mailto:debra.slater@wales.nhs.uk) or [sion.lewis@wales.nhs.uk](mailto:sion.lewis@wales.nhs.uk)

If you would like further information on any other points covered by this letter please do not hesitate to contact me.

On behalf of the Panel, I would like to take this opportunity to wish you every success with your research.

Yours sincerely,



Dr. Nefyn Williams PhD, FRCGP Director of R&D

Copy to:

Sponsor: Hefin Francis Bangor University Bangor LL57 2AS  
[h.francis@bangor.ac.uk](mailto:h.francis@bangor.ac.uk)

Academic Supervisor: Dr Freya Spicer-White Wrexham CAMHS PO Box 2073  
Wrexham Maelor Hospital LL13 7ZA  
[Freya.Spicer@wales.nhs.uk](mailto:Freya.Spicer@wales.nhs.uk)



## Appendix E

### Letter of Invitation



### Letter of Invitation to Participant

**Title of Project:** Parents experiences of the Autistic Spectrum Disorder assessment process when the child did not receive a diagnosis.

Dear Parent/Guardian,

I am writing to tell you about a study being conducted within Betsi Cadwaladr University Health Board.

My colleague, Lesley-Anne Bendik, is looking at parent's experiences of their child going through an assessment for Autistic Spectrum Disorder (ASD) when the outcome did not result in a diagnosis. Following your child's recent assessment, you would be eligible to take part in this research. I am not a member of the research team. However, I am contacting some of my patients to let them know about the research in case they might be interested in learning more.

It is important to know that this letter is not to tell you to join this study. It is your decision. Your participation is voluntary. Whether or not you participate in this study will have no effect on the care you receive from the NHS.

I have enclosed some information for you to read about the study at your leisure.

Once you have read the information, the researcher, Lesley-Anne Bendik, would like to contact you to ask whether you have any questions and to discuss your potential participation in the research in more detail. If you are happy for Lesley-Anne to contact you, please complete and return the opt-in form enclosed with this information.

Alternatively, you can confirm your interest by email ([psp511@bangor.ac.uk](mailto:psp511@bangor.ac.uk)) or telephone (01978 725 242 – please ask for Lesley-Anne Bendik). If Lesley-Anne is unavailable via telephone, please leave a message with your name and contact number and she will get back to you as soon as possible.

Thank you for taking the time to read this information,

Yours Sincerely,

## Llythyr Gwahoddiad i Gyfranwyr

**Teitl y Project:** Profiadau rhieni o'r broses asesu Anhwylder Sbectrwm Awtistig pan na chafodd y plentyn ddiagnosis.

Annwyl Riant/Gwarcheidwad,

Rwy'n ysgrifennu atoch i sôn am astudiaeth a gynhelir ym Mwrdd Iechyd Prifysgol Betsi Cadwaladr.

Mae fy nghydweithiwr, Lesley-Anne Bendik, yn edrych ar brofiadau rhieni o gael eu plentyn yn cael asesiad am Anhwylder Sbectrwm Awtistig (ASD) pan na chafwyd diagnosis ar y diwedd. Yn dilyn asesiad diweddar eich plentyn, byddech chi yn gymwys i gymryd rhan yn yr ymchwil hon. Nid wyf yn aelod o'r tîm ymchwil. Ond rwyf yn cysylltu â rhai o'm cleifion i roi gwybod iddynt am yr ymchwil rhag ofn y byddai ganddynt ddiddordeb mewn dysgu mwy.

Mae'n bwysig ichi wybod nad llythyr i ddweud wrthyfch am gymryd rhan yn yr astudiaeth yw hwn. Eich penderfyniad chi ydyw. Eich dewis chi yw cymryd rhan neu beidio. Ni fydd cymryd rhan neu beidio yn yr astudiaeth hon yn cael unrhyw effaith o gwbl ar y gofal a dderbyniwch gan y GIG.

Rwyf wedi amgáu gwybodaeth am yr astudiaeth i chi ei darllen yn eich amser eich hun.

Unwaith ichi ddarllen y wybodaeth, hoffai'r ymchwilydd, Lesley-Anne Bendik, gysylltu â chi i ofyn a oes gennych unrhyw gwestiynau, ac i drafod y posibilrwydd o gymryd rhan yn yr ymchwil. Os ydych yn fodlon i Lesley-Anne gysylltu â chi, llenwch a dychwelwch y ffurflen gydsynio sydd ynghlwm wrth y wybodaeth hon, os gwelwch yn dda.

Fel arall, gallwch gadarnhau eich diddordeb dros e-bost ([psp511@bangor.ac.uk](mailto:psp511@bangor.ac.uk)) neu ar y ffôn (01978 725 242 – gofynnwch am Lesley-Anne Bendik). Os nad yw Lesley-Anne ar gael ar y ffôn, gadewch neges gyda'ch enw a rhif cyswllt a bydd hi'n cysylltu â chi cyn gynted ag y bo modd.

Diolch i chi am gymryd amser i ddarllen y wybodaeth hon.

Yn gywir,

## Appendix F

### Participant Information Sheet



### Participant Information Sheet

**Title of Project:** Parents experiences of the Autistic Spectrum Disorder assessment process when the child did not receive a diagnosis.

You are invited to take part in a research study being carried out by Bangor University and Betsi Cadwaladr University Health Board (BCUHB). The purpose of this information sheet is to tell you what the research is, why it is being carried out and what it will involve. It is important for you to understand this information before you choose to take part. Please read the information sheet and if you have any questions please email the principal researcher, Lesley-Anne Bendik (psp511@bangor.ac.uk). If you would prefer talk on the phone, please email Lesley-Anne your contact details and she will get back to you.

#### **Research Team**

- Lesley-Anne Bendik (Trainee Clinical Psychologist). Lesley-Anne is currently employed by Betsi Cadwaladr University Health Board and is studying for a Doctorate in Clinical Psychology at Bangor University. This research will contribute to the thesis required to achieve the Doctorate in Clinical Psychology qualification.
- Dr Freya Spicer-White (Lead Clinical Psychologist, Neurodevelopmental Team, East) is supervising this research.

#### **What is the purpose of the study?**

Previous research in the area of Autistic Spectrum Disorders (ASD) has looked at family member's experiences of the ASD assessment process when the outcome is that their child or young person has been given a diagnosis of ASD. There is also research that looks at the experiences of these families after the diagnosis is given in terms of the support they are able to access. However, there is very limited research on the experience of the assessment process and of the support available afterwards to those who go through the same assessment process but for whom do not receive a diagnosis. This refers to occasions when the young person's difficulties are not consistent with, or do not meet the criteria for, a diagnosis of ASD.

The aim of the present study is to explore the experience of parents/guardians whose child/young person is assessed for ASD but who do not receive a diagnosis following the assessment. It is hoped that the outcome of this research will help clinicians understand how best they can support families through the assessment process. It is also hoped that the research will help services to improve their approach to providing good quality information and provide guidelines on how best to feedback a non-diagnosis to family members.

**Why am I being invited to participate?**

We have invited any parents and/or guardians of young people aged 5-19 years who have been through the ASD assessment process within a Child and Adolescent Mental Health Service (CAMHS) in past 12 months and as a result, a diagnosis of ASD was not given. More than one family member can participate if they have been part of the assessment process.

**Do I have to take part?**

No. It is entirely your decision whether or not you want to take part in the research. You can withdraw from the study at any time without giving a reason. If you decide that you don't want to take part or choose to withdraw from the study at any time, this will not affect the care you receive from any service within the NHS.

**What will happen if I/We decide to take part?**

This information sheet will have been given to you during your feedback appointment or sent to you in the post. Once you have read the information sheet and taken some time to think about it, the researcher, Lesley-Anne Bendik, would like to discuss the information with you in further detail and ask whether you have any questions. If you are happy for Lesley-Anne to contact you to discuss your potential participation in the research, please complete the opt-in form provided and return this in the enclosed envelope. Alternatively, you can confirm this by telephone or email. Details of how you can do this can be found on the opt-in form.

If you decide you would like to participate in the research, Lesley-Anne will arrange a convenient time to meet with you. The meeting will take place at the local CAMHS service where you attended for your assessment and feedback appointment. This is to ensure that the interview occurs in a place that you are familiar with and that will be quiet so you can talk about your experiences in private. More than one family member/guardian can participate if they have been involved in the assessment process. Please note in this situation, you will be invited to attend the interview together.

When you meet with Lesley-Anne, she will ask you to read and sign a consent form. You will have the opportunity to ask Lesley-Anne any questions about the research before you sign the form. If you are happy to provide consent to take part, Lesley-Anne will ask you some questions about the age and gender of your child, your relationship to them and how long the assessment process has taken. She will then ask you some short questions about your experience of the process in an informal interview. Please be assured there are no right or wrong answers, and should you wish to not answer a question or stop the interview at any time this is okay.

The same questions will be asked to all participants. These questions have been approved by the ethics committee at Bangor University and Betsi Cadwaladr University Health Board. Lesley-Anne will record all interviews on a digital audio recorder. This is to keep a record of the interview and help Lesley-Anne to listen to your experiences without interrupting you or writing notes.

The interview will take approximately 45-90minutes. You will be given the opportunity to have breaks during the interview if needed.

**What are the possible risks or disadvantages of taking part?**

We hope that this study will not cause you any distress. However, we are aware that sharing personal experiences can be difficult and on occasions can cause upset, stress or worry. If you feel upset or distressed at any point during the interview, it is important that you make Lesley-Anne aware. Lesley-Anne is a Trainee Clinical Psychologist and has the skills to manage difficult emotional responses. You are encouraged to say if there are questions that you do not want to answer or if you would like to stop the interview at any point.

Should you feel upset or distressed during the interview or afterwards as a result of the interview, you are advised to talk to Lesley-Anne, who can sign post you access the appropriate support or to contact your GP.

It is difficult to include all of the information you provide in the final results. Therefore, whilst some of your experiences may be included, this is not guaranteed as it can be hard to include everyone's experiences. This does not mean that the experiences you share with us are not of great value.

**What are the possible benefits of taking part?**

You will not benefit directly from taking part in this research, however you may find it helpful or enjoyable to share your experiences. You may also find it enjoyable to be part of a research project that aims to understand and improve the experiences of people who go through the ASD diagnosis process.

The research team would like to offer a token gesture of a £10 voucher to all participants for sharing their time and experiences to improve our professional knowledge and help us understand how we can improve patients and family members experience of the ASD assessment process in the future. As the interview will be held at your local CAMHS service, your travel expenses will be covered.

**Will my information be kept private and confidential?**

Yes. All the information that you share with Lesley-Anne will be kept private and confidential within the research team. There is one exception to this and that is if you disclose any information that you or any other person is directly or indirectly at risk of harm, or causing harm to others. In this circumstance, Lesley-Anne will have to breach confidentiality to ensure you are given the appropriate support. In the first instance, Lesley-Anne will discuss this information with the Lead Clinical Psychologist, Dr Freya Spicer-White. Following this, Lesley-Anne Bendik or Dr Freya Spicer-White may need to share this information with the local Child Protection Team in line with NHS policy and will seek further advice from this team as appropriate. Lesley-Anne will discuss this with you in further detail if this situation arises.

Throughout the research all participants will be assigned a participant number to protect their identity. The research team will keep a record of the participant's name and corresponding participant number. We keep this record so that should you wish to withdraw your information from the study it can be located.

The interviews will be recorded on a digital recorder and will be transcribed anonymously onto an encrypted device following the interview. All information collected throughout the project will strictly be stored and managed in accordance with BCUHBs information governance policy and the Data Protection Act (1998).

When the results of the study are written up, direct quotes from your interview may be included. However, the researchers have to follow strict guidelines to ensure that your personal information is not included and that no-one reading the report will be able to identify you from the quotes or information included. For example, your name will be changed and any identifiable information will be removed.

### **What will happen to the recordings of what I have said?**

Lesley-Anne will record your interview on a digital recorder. After the interview, this will be kept in a locked filing cabinet until it is transcribed onto an encrypted device and then deleted from the recorder; the information will be anonymised prior to being transcribed. This means that you will be identified by a participant number rather than your name. The encrypted device can only be accessed by the research team.

Upon completion of this study, the research team may wish to access the information for future research studies. If so, they have to contact you again to ask for your consent. The research team will destroy the transcript of your interview 5 years after the study has finished.

### **What will happen to the results of the research?**

The results of the research will be summarised and sent to you in a leaflet. You will also be invited to contact Lesley-Anne to discuss the results in more detail if you wish.

This research is being conducted as part of a thesis for a professional Doctorate of Clinical Psychology and the findings will be written and submitted to Bangor University. The research will also present the findings at an annual stake-holders conference organised by the North Wales Clinical Psychology Programme at Bangor University. In addition, the results will be written for publication in at least one research journal for the benefit of other professionals and future practice.

### **Welsh Language**

All written information about the research study will be provided in Welsh and English. However, if you choose to take part in the research, please note that the interview will only be conducted in English, as unfortunately Lesley-Anne can not speak Welsh.

### **What will happen if I don't want to carry on with the study?**

It is entirely up to whether you want to take part in the research. If you do choose to take part, you can change your mind at any time and you do not have to give a reason. This will not affect the care you receive within the NHS. If you wish to withdraw from the study following your interview, your information will be removed without question and you will still receive the £10 voucher for your time.

### **Who is funding the research?**

This research is being funded by the North Wales Clinical Psychology Programme at Bangor University.

**Who has reviewed the study?**

All research conducted within the NHS is examined at by independent group of people who come together to form a 'Research Ethics Committee'. This committee examine all research before is it conducted to protect your interests and ensure is it conducted in an ethical manner. This research study has been granted ethical approval by the Bangor School of Psychology Ethics and Governance Committee and the Health Research Authority Wales (Rec 5) Committee.

**What if there is a problem?**

If you have any concerns about any aspect of taking part in this study, please contact a member of the research team Lesley-Anne Bendik ([psp511@bangor.ac.uk](mailto:psp511@bangor.ac.uk)) or Dr Freya Spicer-White ([Freya.Spicer@wales.nhs.uk](mailto:Freya.Spicer@wales.nhs.uk)). They will try to answer any questions or concerns you have about the research. However, if you feel your concerns have not been addressed and you wish to make a formal complaint you are encouraged to use the contact details provided below.

For a University complaint:           Hefin Francis (School Manager)  
School of Psychology  
Adeilad Brigantia  
Penrallt Road  
Gwynedd LL57 2AS  
Email: [h.francis@bangor.ac.uk](mailto:h.francis@bangor.ac.uk)  
Tel: 01248 388339

For an NHS complaint:               Concerns Team  
Betsi Cadwaladr University Health Board  
Ysbyty Gwynedd  
Bangor  
Gwynedd  
LL57 2PW  
Email: [ConcernsTeam.bcu@wales.nhs.uk](mailto:ConcernsTeam.bcu@wales.nhs.uk)  
Tel: 01248 384194

**Further information and contact details**

If you have any questions of require more information about the research before you deciding whether you would like to part, please do not hesitate to contact Lesley-Anne ([psp511@bangor.ac.uk](mailto:psp511@bangor.ac.uk)).

Thank you for taking the time to read this information.

## Taflen wybodaeth i rai sy'n cymryd rhan

**Teitl y Project:** Profiadau rhieni o'r broses asesu Anhwylder Sbectrwm Awtistig pan na chafodd y plentyn ddiagnosis.

Gwahoddir chi i gymryd rhan mewn astudiaeth ymchwil a gynhelir gan Brifysgol Bangor a Bwrdd Iechyd Prifysgol Betsi Cadwaladr (BCUHB). Diben y daflen wybodaeth hon yw dweud wrthyfych beth yw yr ymchwil, pam mae'n cael ei chynnal, a'r hyn fydd yn digwydd yn ystod yr ymchwil. Mae'n bwysig eich bod yn deall y wybodaeth hon cyn dewis cymryd rhan. Darllenwch y daflen wybodaeth ac, os oes gennych unrhyw gwestiynau, anfonwch e-bost at y prif ymchwilydd, Lesley-Anne Bendik (psp511@bangor.ac.uk). Os yw'n well gennych siarad ar y ffôn, e-bostiwch eich manylion cyswllt at Lesley-Anne ac fe wnaiff hi gysylltu â chi.

### Y Tîm Ymchwil

- Lesley-Anne Bendik (Seicolegydd Clinigol dan Hyfforddiant). Mae Lesley-Anne ar hyn o bryd yn cael ei chyflogi gan Fwrdd Iechyd Prifysgol Betsi Cadwaladr ac yn astudio am ddoethuriaeth mewn Seicoleg Glinigol ym Mhrifysgol Bangor. Bydd yr ymchwil hon yn cyfrannu at y thesis sy'n angenrheidiol i ennill y cymhwyster doethuriaeth mewn Seicoleg Glinigol.
- Mae Dr Freya Spicer-White (Prif Seicolegydd Clinigol, Tîm Niwroddatblygiadol, Dwyrain) yn goruchwylio'r ymchwil hon.

### Beth yw diben yr astudiaeth?

Mae ymchwil blaenorol ym maes Anhwylder Sbectrwm Awtistig (ASD) wedi edrych ar brofiadau aelodau o'r teulu o'r broses asesu ASD pan mae eu plentyn neu eu person ifanc yn cael diagnosis o ASD. Mae yna hefyd ymchwil sy'n edrych ar brofiadau'r teuluoedd hyn yn dilyn derbyn y diagnosis o ran y gefnogaeth sydd ar gael iddynt. Fodd bynnag, ychydig iawn o ymchwil sydd wedi ei wneud i brofiadau rhai sy'n mynd drwy'r un broses asesu, ond nad ydynt yn derbyn diagnosis o'r broses asesu ei hun, a'r gefnogaeth ar ôl hynny. Mae hyn yn cyfeirio at achlysuron pan nad yw anawsterau'r person ifanc yn gyson neu'n cwrdd â'r meini prawf ar gyfer diagnosis o ASD.

Amcan yr astudiaeth bresennol yw archwilio profiad rhieni/gwarcheidwaid yr aserir eu plentyn/person ifanc am ASD ond nad ydynt yn derbyn diagnosis yn dilyn yr asesiad. Gobeithir y bydd canlyniad yr ymchwil yn helpu clinigwyr i ddeall sut orau i gefnogi teuluoedd drwy'r broses asesu. Gobeithir hefyd y bydd yr ymchwil yn helpu gwasanaethau i wella eu dull o roi gwybodaeth o ansawdd uchel a darparu canllawiau ar sut i adrodd am ddiffyg diagnosis i aelodau o'r teulu.

### Pam rydw i'n cael gwahoddiad i gymryd rhan?

Rydym wedi gwahodd rhieni a/neu gwarcheidwaid pobl ifanc rhwng 5-19 oed sydd wedi bod drwy'r broses asesu ASD mewn Gwasanaeth Iechyd Meddwl Plant a'r Glasoed (CAMHS) yn y 12 mis diwethaf lle na roddwyd diagnosis o ASD. Gall mwy nag un aelod o'r teulu gymryd rhan os ydynt wedi bod yn rhan o'r broses asesu.



**Oes rhaid imi gymryd rhan?**

Nac oes. Eich penderfyniad chi yn unig yw a ydych eisiau cymryd rhan yn yr ymchwil. Gallwch dynnu'n ôl o'r astudiaeth ar unrhyw adeg heb roi rheswm. Os penderfynwch nad ydych am gymryd rhan, neu os ydych yn penderfynu rhoi'r gorau iddi ar unrhyw adeg, ni fydd hynny'n effeithio ar y gofal a dderbyniwch gan unrhyw wasanaeth yn y GIG.

**Beth fydd yn digwydd os byddaf i / byddwn ni yn penderfynu cymryd rhan?**

Bydd y daflen wybodaeth hon wedi ei rhoi ichi yn ystod eich apwyntiad adborth, neu ei hanfon atoch drwy'r post. Unwaith ichi ddarllen y daflen wybodaeth, a chymryd amser i feddwl am y peth, hoffai'r ymchwilydd, Lesley-Anne Bendik, drafod y wybodaeth gyda chi a gofyn a oes gennych unrhyw gwestiynau. Os ydych yn fodlon i Lesley-Anne gysylltu â chi i drafod cymryd rhan yn yr ymchwil, llenwch y ffurflen gydsynio a ddarparwyd, a'i dychwelyd yn yr amlen amgaeedig. Fel arall, gallwch gadarnhau hyn dros y ffôn neu drwy e-bost. Ceir manylion am sut i wneud hyn ar y ffurflen gydsynio.

Os penderfynwch yr hoffech gymryd rhan yn yr ymchwil, bydd Lesley-Anne yn trefnu amser cyfleus i gwrdd â chi. Cynhelir y cyfarfod yn y gwasanaeth CAMHS lleol lle cynhaliwyd eich asesiad a'ch apwyntiad adborth. Pwrpas hyn yw sicrhau bod y cyfweiliad yn digwydd mewn lle yr ydych chi'n gyfarwydd ag ef, ac mewn lle tawel fel y gallwch chi drafod eich profiadau mewn preifatrwydd. Gall mwy nag un aelod o'r teulu / gwarcheidwad gymryd rhan os ydynt wedi bod yn rhan o'r broses asesu. Yn y sefyllfa hon, ceuwch wahoddiad i gael eich cyfweld gyda'ch gilydd.

Pan fyddwch yn cyfarfod â Lesley-Anne, bydd hi'n gofyn ichi ddarllen ac arwyddo ffurflen gydsynio. Ceuwch gyfle i ofyn unrhyw gwestiynau am yr ymchwil i Lesley-Anne cyn ichi arwyddo'r ffurflen. Os ydych yn fodlon cydsynio i gymryd rhan, bydd Lesley-Anne yn gofyn cwestiynau ichi ynglŷn ag oedran a gender eich plentyn, eich perthynas â nhw a faint o amser mae'r broses asesu wedi ei gymryd. Bydd hi wedyn gofyn cwestiynau byr ichi am eich profiad o'r broses mewn cyfweiliad anffurfiol. Cofiwch nad oes atebion cywir neu anghywir, ac mae hi'n berffaith iawn ichi beidio ateb cwestiwn neu ddod â'r cyfweiliad i ben ar unrhyw adeg.

Gofynnir yr un cwestiynau i bawb sy'n cymryd rhan. Mae'r cwestiynau hyn wedi eu cymeradwyo gan bwyllgor moeseg Prifysgol Bangor a Bwrdd Iechyd Prifysgol Betsi Cadwaladr. Bydd Lesley-Anne yn recordio pob cyfweiliad ar beiriant recordio digidol. Diben hyn yw cadw cofnod o'r cyfweiliad a helpu Lesley-Anne i wrando ar eich profiadau heb dorri ar draws neu wneud nodiadau.

Bydd y cyfweiliad yn para tua 45-90 munud. Bydd cyfle i gymryd seibiannau yn ystod y cyfweiliad os oes angen.

**Beth yw'r risgiau neu'r anfanteision posibl o gymryd rhan?**

Gobeithiwn na fydd yr astudiaeth hon yn peri unrhyw ofid ichi. Fodd bynnag, rydym yn ymwybodol y gall rhannu profiadau personol fod yn anodd ac ar brydiau gall beri gofid, straen, neu bryder. Os ydych yn teimlo'n boenus neu'n ofidus ar unrhyw adeg yn ystod y cyfweiliad, mae'n bwysig eich bod yn dweud hynny wrth Lesley-Anne. Mae Lesley-Anne yn Seicolegydd Clinigol dan Hyfforddiant, ac mae ganddi'r sgiliau i reoli ymatebion

emosiynol anodd. Fe'ch anogir i ddweud os oes unrhyw gwestiynau y byddai'n well gennyh beidio â'u hateb, neu os hoffech stopio'r cyfweiliad ar unrhyw adeg.

Os ydych yn teimlo'n boenus neu'n ofidus yn ystod y cyfweiliad neu wedyn oherwydd y cyfweiliad, fe'ch cynghorir i siarad â Lesley-Anne, a all eich cyfeirio at gefnogaeth addas neu at eich meddyg teulu.

Mae'n anodd cynnwys yr holl wybodaeth a roddwch yn y canlyniadau terfynol. Felly, er y gall rhai o'ch profiadau gael eu cynnwys, nid oes sicrwydd o hynny gan y gall fod yn anodd cynnwys profiadau pawb. Nid yw hynny'n golygu nad yw'r profiadau a rannwch gyda ni yn werthfawr iawn.

### **Beth yw'r manteision posibl o gymryd rhan?**

Ni fyddwch yn cael budd uniongyrchol o gymryd rhan yn yr ymchwil, ond efallai y bydd rhannu eich profiadau yn gymorth neu'n bleserus. Efallai hefyd y cewch fwynhad o fod yn rhan o broject ymchwil sy'n ceisio deall a gwella profiadau pobl sy'n mynd drwy'r broses ddiagnosis ASD.

Hoffai'r tîm ymchwil gynnig taleb £10 fel arwydd o'n diolchgarwch i bob cyfrannwr am rannu eu hamser a'u profiadau er mwyn gwella ein gwybodaeth broffesiynol a'n helpu i ddeall sut y gallwn wella profiadau cleifion a'u teuluoedd o'r broses asesu ASD yn y dyfodol. Gan y bydd y cyfweiliad yn cael ei gynnal yn eich gwasanaeth CAMHS lleol, telir costau teithio.

### **Fydd y wybodaeth amdanaf yn cael ei chadw'n breifat a chyfrinachol?**

Bydd. Cedwir unrhyw wybodaeth a rannwch gyda Lesley-Anne yn breifat a chyfrinachol o fewn y tîm ymchwil. Yr unig eithriad i hyn yw pe baech yn datgelu unrhyw wybodaeth eich bod chi neu unrhyw un arall mewn perygl uniongyrchol neu anuniongyrchol o niwed, neu o achosi niwed i eraill. Mewn achos fel hyn, byddai'n rhaid i Lesley-Anne dorri cyfrinachedd er mwyn sicrhau eich bod chi'n cael cefnogaeth addas. Yn y lle cyntaf, bydd Lesley-Anne yn trafod y wybodaeth gyda'r Prif Seicolegydd Clinigol, Dr Freya Spicer-White. Yn dilyn hyn, efallai y byddai angen i Lesley-Anne neu Dr Freya Spicer-White rannu'r wybodaeth hon gyda'r Tîm Gwarchod Plant lleol yn unol â pholisi'r GIG, a byddant yn ceisio rhagor o gyngor gan y tîm hwn fel bo'n briodol. Bydd Lesley-Anne yn trafod hyn yn fanylach gyda chi os bydd y sefyllfa'n codi.

Drwy gydol yr ymchwil bydd pob cyfrannwr yn cael rhif cyfrannwr er mwyn gwarchod pwy ydynt. Bydd y tîm ymchwil yn cadw cofnod o enw'r cyfrannwr a'i rif cyfatebol. Rydym yn cadw'r cofnod hwn fel y gellir cael gafael arno'n hawdd pe byddech yn dymuno tynnu'n ôl o'r astudiaeth.

Caiff y cyfweiliadau eu recordio ar recordydd llais digidol a'u trawsgrifio'n ddiennw ar ddyfais wedi eu hamgryptio ar ôl y cyfweiliad. Bydd yr holl wybodaeth a gesglir drwy gydol y project yn cael ei storio a'i rheoli yn unol â pholisi rheoli gwybodaeth Bwrdd Iechyd Prifysgol Betsi Cadwaladr a'r Ddeddf Diogelu Data (1998).

Pan fydd canlyniadau'r astudiaeth yn cael eu hysgrifennu, efallai y defnyddir dyfyniadau uniongyrchol o'ch cyfweiliad. Fodd bynnag, rhaid i'r ymchwilwyr ddilyn canllawiau llym er mwyn sicrhau nad yw eich gwybodaeth bersonol yn cael ei chynnwys ac na fudd unrhyw un fydd yn darllen yr adroddiad yn gallu eich adnabod o'r dyfyniadau na'r

wybodaeth. Er enghraifft, caiff eich enw ei newid a bydd y manylion personol yn cael eu dileu.

### **Beth fydd yn digwydd i'r recordiadau o'r hyn ddywedais i?**

Bydd Lesley-Anne yn recordio eich cyfweiliad ar recordydd digidol. Ar ôl y cyfweiliad, cedwir hwn mewn cwpwrdd ffeilio dan glo tan iddo gael ei drawsgrifio ar ddyfais wedi eu hamgryptio ac yna caiff ei ddileu oddi ar y recordydd; gwneir y wybodaeth yn ddiennw cyn ei thrawsgrifio. Golyga hyn y cewch eich adnabod wrth rif cyfrannwr yn hytrach na'ch enw. Dim ond aelodau'r tîm ymchwil fydd yn gallu cael mynediad at y ddyfais wedi'i hamgryptio.

Unwaith i'r astudiaeth ddod i ben, efallai yr hoffai'r tîm ymchwil gael mynediad at y wybodaeth at ddibenion astudiaethau ymchwil yn y dyfodol. Os felly, rhaid iddynt gysylltu â chi eto er mwyn gofyn am eich caniatâd. Bydd y tîm ymchwil yn dinistrio trawsgrifiad eich cyfweiliad 5 mlynedd ar ôl i'r astudiaeth ddod i ben.

### **Beth fydd yn digwydd i ganlyniadau'r ymchwil?**

Bydd canlyniadau'r ymchwil yn cael eu crynhoi a'u hanfon atoch mewn pamffled. Bydd yna hefyd wahoddiad ichi gysylltu â Lesley-Anne i drafod y canlyniadau, os hoffech wneud hynny.

Mae'r ymchwil hon yn cael ei chynnal fel rhan o thesis ar gyfer Doethuriaeth broffesiynol mewn Seicoleg Glinigol a bydd y canlyniadau'n cael eu hysgrifennu a'u cyflwyno i Brifysgol Bangor. Bydd yr ymchwil hefyd yn cyflwyno'r canlyniadau mewn cynhadledd flynyddol i fudd-ddeiliaid a drefnir gan Raglen Seicoleg Glinigol Gogledd Cymru ym Mhrifysgol Bangor. Hefyd, caiff y canlyniadau eu hysgrifennu a'u cyhoeddi mewn o leiaf un cyfnodolyn ymchwil er budd gweithwyr proffesiynol eraill ac ymarfer yn y dyfodol.

### **Yr Iaith Gymraeg**

Bydd yr holl wybodaeth ysgrifenedig am yr astudiaeth ymchwil yn cael ei darparu yn Gymraeg ac yn Saesneg. Fodd bynnag, os dewiswch gymryd rhan yn yr ymchwil, nodwch mai dim ond yn Saesneg y gall y cyfweiliad gael ei gynnal gan nad yw Lesley-Anne, yn anffodus, yn gallu siarad Gymraeg.

### **Beth fydd yn digwydd os na fyddaf yn dymuno parhau â'r astudiaeth?**

Chi yn unig sydd i benderfynu a ydych eisiau cymryd rhan yn yr ymchwil ai peidio. Os ydych yn dewis cymryd rhan, gallwch newid eich meddwl ar unrhyw adeg ac nid oes rhaid ichi roi rheswm. Ni fydd hyn yn effeithio ar y gofal a gewch gan y GIG. Os hoffech dynnu'n ôl o'r astudiaeth yn dilyn eich cyfweiliad, dilëir eich gwybodaeth yn ddi-gwestiwn a byddwch yn dal yn derbyn y daleb £10 am eich amser.

### **Pwy sy'n cyllido'r ymchwil?**

Ariennir yr ymchwil hon gan Raglen Seicoleg Glinigol Gogledd Cymru ym Mhrifysgol Bangor.

### **Pwy sydd wedi adolygu'r astudiaeth?**

Mae'r holl ymchwil a gynhelir o fewn y GIG yn cael ei archwilio gan grŵp annibynnol o bobl sy'n dod at ei gilydd i ffurfio 'Pwyllgor Moeseg Ymchwil'. Mae'r pwyllgor hwn yn archwilio pob ymchwil cyn iddi gael ei chynnal er mwyn gwarchod eich buddiannau a

sicrhau ei bod yn cael ei chynnal mewn ffordd foesol. Mae'r astudiaeth ymchwil hon wedi cael cymeradwyaeth foesebol gan Bwyllgor Moeleg Ymchwil a Llywodraethol Ysgol Seicoleg Bangor a Phwyllgor Awdurdod Ymchwil Iechyd Cymru (Rec 5).

**Beth os bydd problem yn codi?**

Os oes gennych unrhyw bryderon ynghylch unrhyw agwedd ar gymryd rhan yn yr astudiaeth hon, cysylltwch ag aelod o'r tîm ymchwil, Lesley-Anne Bendik (psp511@bangor.ac.uk) neu Dr Freya Spicer-White (Freya.Spicer@wales.nhs.uk). Byddant yn ceisio ateb unrhyw gwestiynau neu bryderon sydd gennych yn glŷn â'r ymchwil. Fodd bynnag, os ydych yn teimlo nad yw eich pryderon wedi cael gwrandawriad teg a'ch bod eisiau gwneud cwyn ffurfiol, defnyddiwch y manylion cyswllt isod:

Yn achos cwyn am y Brifysgol:      Hefin Francis (Rheolwr Ysgol)  
Ysgol Seicoleg  
Adeilad Brigantia  
Ffordd Penrallt  
Gwynedd LL57 2AS  
E-bost: h.francis@bangor.ac.uk  
Ffôn: 01248 388339

Yn achos cwyn am y GIG:              Tîm Pryderon  
Bwrdd Iechyd Prifysgol Betsi Cadwaladr  
Ysbyty Gwynedd  
Bangor  
Gwynedd  
LL57 2PW  
E-bost: ConcernsTeam.bcu@wales.nhs.uk  
Ffôn: 01248 384194

**Rhagor o wybodaeth a manylion cysylltu**

Os oes gennych unrhyw gwestiynau, neu os hoffech gael rhagor o wybodaeth am yr ymchwil cyn penderfynu a hoffech gymryd rhan, mae croeso ichi gysylltu â Lesley-Anne (psp511@bangor.ac.uk).

Diolch am roi'ch amser i ddarllen y wybodaeth hon.

## Appendix G

### Opt-In Form



### Opt-in Form

**Title of Project:** Experience of the ASD assessment process when a diagnosis is not received.

**Name of Researcher:** Lesley-Anne Bendik (Trainee Clinical Psychologist)

**Supervised By:** Dr Freya Spicer-White (Lead Clinical Psychologist)

You will have been given an information sheet about the above research study. The researcher, Lesley-Anne Bendik, would like to give you time to read this information and then contact you to ask whether you have any questions and to discuss whether you might like to participate in this research.

If you have read the participant information sheet and are happy to be contacted by Lesley-Anne Bendik (principal researcher) to discuss the research and your potential participation, please leave your contact details and signature at the bottom of this form. The completed form should be returned in the addressed envelope provided. Once this has been received, Lesley-Anne will contact you to discuss the research.

Alternatively, you can email or telephone Lesley-Anne Bendik at ([psp511@bangor.ac.uk](mailto:psp511@bangor.ac.uk)) or (01978 725 242) to confirm if you are happy for Lesley-Anne to contact you. If Lesley-Anne is unavailable via telephone, please leave a message with your name and contact number and she will get back to you as soon as possible.

#### **My Contact Details:**

Name: \_\_\_\_\_

Telephone (home): \_\_\_\_\_

Telephone (mobile): \_\_\_\_\_

Email: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

**Further information:** If you have any questions or require more information about this study please contact: Lesley-Anne Bendik via e-mail [psp511@bangor.ac.uk](mailto:psp511@bangor.ac.uk)

**Complaints:** Any complaints concerning the conduct of this research should be addressed to: Mr Hefin Francis, School Manager, School of Psychology, Bangor University, Gwynedd, LL57-2AS.



## Ffurflen gymryd rhan

**Teitl y Project:** Profiad o'r broses asesu Anhwylder Sbectrwm Awtistig pan na dderbynnir diagnosis.

**Enw'r ymchwilydd:** Lesley-Anne Bendik (Seicolegydd Clinigol dan Hyfforddiant)

**Goruchwylir gan:** Dr Freya Spicer-White (Prif Seicolegydd Clinigol)

Byddwch wedi cael taflen wybodaeth am yr astudiaeth ymchwil uchod. Hoffai'r ymchwilydd, Lesley-Anne Bendik, roi amser ichi ddarllen y wybodaeth hon ac yna fe hoffai gysylltu â chi i ofyn a oes gennych unrhyw gwestiynau ac i drafod a hoffech chi gymryd rhan yn yr ymchwil.

Os ydych wedi darllen y daflen wybodaeth ac yn fodlon i Lesley-Anne Bendik (prif ymchwilydd) gysylltu â chi i drafod yr ymchwil a'r posibilrwydd y gallech chi gymryd rhan, rhowch eich manylion cyswllt a'ch llofnod ar waelod y ffurflen hon. Ar ôl i chi ei llenwi, dylid dychwelyd y ffurflen yn yr amlen a ddarparwyd. Unwaith i ni dderbyn hon, bydd Lesley-Anne yn cysylltu â chi i drafod yr ymchwil.

Fel arall, gallwch e-bostio neu ffonio Lesley-Anne Bendik ar (psp511@bangor.ac.uk) neu (01978 725 242) i gadarnhau eich bod yn fodlon i Lesley-Anne gysylltu â chi. Os nad yw Lesley-Anne ar gael ar y ffôn, gadewch neges gyda'ch enw a rhif cyswllt a bydd hi'n cysylltu â chi cyn gynted ag y bo modd.

### **Fy manylion cyswllt:**

Enw: \_\_\_\_\_

Rhif ffôn (cartref): \_\_\_\_\_

Rhif ffôn (symudol): \_\_\_\_\_

E-bost: \_\_\_\_\_

Llofnod: \_\_\_\_\_ Dyddiad: \_\_\_\_\_

**Gwybodaeth bellach:** Os oes gennych unrhyw gwestiynau, neu os hoffech gael rhagor o wybodaeth am yr astudiaeth hon, cysylltwch â: Lesley-Anne Bendik dros e-bost psp511@bangor.ac.uk

**Cwynion:** Dylech anfon unrhyw gwynion ynglŷn â'r modd y cynhaliwyd yr astudiaeth hon at: Mr Hefin Francis, Rheolwr yr Ysgol, Ysgol Seicoleg, Prifysgol Bangor, Bangor, Gwynedd, LL57 2AS.

## Appendix H Telephone Protocol



### Telephone Protocol

**Title of Project:** Parents experiences of the Autistic Spectrum Disorder assessment process when the child did not receive a diagnosis.

Hello,

My name is Lesley-Anne Bendik. I am calling with regards to the recent appointments you attended at (insert relevant CAMHS team) with your (son/daughter) for the (his/her) Autism assessment.

I understand that you recently saw (insert clinicians name) and that during your feedback appointment (he/she) gave you an information sheet regarding some research that is currently taking place. The research is looking at the experiences of parents whose child was assessed for Autism, and as a result it was felt that this diagnosis did not fit their child's difficulties.

I wonder if you have had time to read the information sheet, and whether you have any questions you would like to ask... and whether you think this might be something you would like to be involved with. Participation in the research is completely voluntary and will not affect any aspect of your care from the service if you decide not to take part...

...If the individual decides they would like to be involved a suitable time will be arranged to meet with them at their local CAMHS facility.

...If the individual does not want to be involved, they will be thanked for their time and reassured again that their decision will not be recorded and will have no influence on the care they receive.

## Appendix I

### Participant Consent Form



**GIG**  
CYMRU  
**NHS**  
WALES

Bwrdd Iechyd Prifysgol  
Betsi Cadwaladr  
University Health Board

### Participant Consent Form

**Title of Project:** Parents experiences of the Autistic Spectrum Disorder assessment process when the child did not receive a diagnosis.

**Name of Researcher:** Lesley-Anne Bendik (Trainee Clinical Psychologist)

**Supervised By:** Dr Freya Spicer-White (Lead Clinical Psychologist)

Please put your initials in the box if you agree to the following statements:

1. I confirm that I have read and understand the information sheet (dated: \_\_\_\_\_) for the above study.
2. I have had time to consider the information and have had the opportunity to ask Lesley-Anne to any questions I had and have had these answered.
3. I understand that my participation is voluntary and that I can withdraw at any time without giving a reason. I understand that withdrawal from the study will not affect my/my child's care in the NHS.
4. I agree for Lesley-Anne to record my interview.
5. I understand that all the information I provide will be made anonymous and will be stored securely in line with the Betsi Cadwaladr University Health Board Information Governance policy and the Data Protection Act (1998).
6. I understand that specific quotes that I say during the interview may be included in the final report. However, these will be carefully selected to ensure that I cannot be identified.
7. I understand that if I disclose any information that I, or any other person, is directly or indirectly at risk of harm, or causing harm to others, Lesley-Anne will have to breach confidentiality. In this situation, Lesley-Anne will share this information with the Lead Clinical Psychologist (Dr Freya Spicer-White) and potentially with the local Child Protection Team to seek further advice, in line with NHS policy.
8. I agree to take part in the above study.

Name of Participant: \_\_\_\_\_ Date: \_\_\_\_\_ Signature: \_\_\_\_\_

Name of Researcher: \_\_\_\_\_ Date: \_\_\_\_\_ Signature: \_\_\_\_\_



**Further information:** If you have any questions or require more information about this study please contact: Lesley-Anne Bendik via e-mail [psp511@bangor.ac.uk](mailto:psp511@bangor.ac.uk)

**Complaints:** Any complaints concerning the conduct of this research should be addressed to: Mr Hefin Francis, School Manager, School of Psychology, Bangor University, Gwynedd, LL57 2AS.

### **Ffurflen Gydsynio i Rai sy'n Cymryd Rhan**

**Teitl y Project:** Profiadau rhieni o'r broses asesu Anhwylder Sbectrwm Awtistig pan na chafodd y plentyn ddiagnosis.

**Enw'r Ymchwilydd:** Lesley-Anne Bendik (Seicolegydd Clinigol dan Hyfforddiant)

**Goruchwylir gan:** Dr Freya Spicer-White (Prif Seicolegydd Clinigol)

**Rhowch eich blaenlythrennau yn y blwch os ydych yn cytuno â'r gosodiadau isod:**

1. Cadarnhaf fy mod wedi darllen a deall y daflen wybodaeth (dyddiedig: \_\_\_\_\_) ar gyfer yr astudiaeth uchod.
2. Rwyf wedi cael amser i ystyried y wybodaeth ac rwyf wedi cael y cyfle i ofyn unrhyw gwestiynau i Lesley-Anne, ac rwyf wedi cael atebion i'r cwestiynau hyn.
3. Rwy'n deall fy mod yn cymryd rhan o'm gwirfodd, a bod gennyf hawl i dynnu'n ôl ar unrhyw adeg heb roi rheswm. Deallaf na fyddai tynnu'n ôl o'r astudiaeth yn effeithio ar fy ngofal i na gofal fy mhlentyn yn y GIG.
4. Cytunaf i Lesley-Anne recordio fy nghyfweliad.
5. Deallaf y bydd yr holl wybodaeth a roddaf yn ddiennw ac yn cael ei chadw'n ddiogel yn unol â pholisi rheoli gwybodaeth Bwrdd Iechyd Prifysgol Betsi Cadwaladr a'r Ddeddf Diogelu Data (1998).
6. Rwy'n deall ei bod yn bosibl y caiff dyfyniadau penodol gennyf eu cynnwys yn yr adroddiad terfynol. Fodd bynnag, dewisir y rhain yn ofalus fel na fydd modd fy adnabod trwyddynt.
7. Pe bawn yn datgelu unrhyw wybodaeth fy mod i neu rywun arall mewn perygl uniongyrchol neu anuniongyrchol o niwed, neu achosi niwed i eraill, rwy'n deall y byddai'n rhaid i Lesley-Anne dorri cyfrinachedd. Yn y sefyllfa hon, bydd Lesley-Anne yn rhannu'r wybodaeth gyda'r Prif Seicolegydd Clinigol (Dr Freya Spicer-White), ac o bosibl gyda'r Tîm Gwarchod Plant lleol er mwyn cael cyngor pellach, yn unol â pholisi'r GIG.
8. Rwy'n cytuno i gymryd rhan yn yr astudiaeth uchod.

Enw'r Cyfrannwr: \_\_\_\_\_ Dyddiad: \_\_\_\_\_ Llofnod: \_\_\_\_\_

Enw'r Ymchwilydd: \_\_\_\_\_ Dyddiad: \_\_\_\_\_ Llofnod: \_\_\_\_\_

**Gwybodaeth bellach:** Os oes gennych unrhyw gwestiynau, neu os hoffech gael rhagor o wybodaeth am yr astudiaeth hon, cysylltwch â: Lesley-Anne Bendik dros e-bost [psp511@bangor.ac.uk](mailto:psp511@bangor.ac.uk)

**Cwynion:** Dylech anfon unrhyw gwynion ynglŷn â'r modd y cynhaliwyd yr astudiaeth hon at: Mr Hefin Francis, Rheolwr yr Ysgol, Ysgol Seicoleg, Prifysgol Bangor, Bangor, Gwynedd, LL57 2AS.

## Appendix J

### Interview Schedule



### Interview Schedule

**1. Before we start the interview I would like to ask you some questions about yourself and your son/daughter.**

- Please can you tell me your relationship to your child?
- How old was your child at the time they were assessed?
- Which family member/guardian attended the assessment and feedback appointment?
- How long did you have to wait to be seen after you were referred for an assessment?
- How long did the assessment take? (months/number of appointments)
- How many different professionals did you see?

**2. What brought you to want the assessment?**

- When did you first notice the difficulties?
- Who first noticed these difficulties?
- What difficulties did you notice?
- Whose suggestion was it to go for an Ax?
- What were your thoughts about attending the assessment?
- What did you hope to gain from the outcome?
- How did you feel when you first realised your child was displaying some difficulties?
- Were there any barriers / obstacles to your child having an assessment? If so, what helped you to overcome these barriers?

**3. What was the assessment process like?**

- How did you find the assessment?
- Did you understand the assessment process?
- Did you feel heard, included and understood throughout the process?
- Did you feel your child was heard, included and understood?
- Did you feel your responses helped or hindered the process and the outcome in any way?
- Did you encounter any problems during the assessment process?
- Was there anything about the process that surprised you?

**4. What was it like hearing the outcome of the Ax? What was the feedback appointment like?**

- How did you feel when you heard the outcome of the assessment?
- Was the outcome explained fully?
- Did you understand the explanation?
- How did you feel in the days/weeks/months following the outcome?

- How did you feel about the level of support you were offered?
- Have you noticed any impact of this outcome on yourself, your child, your family?
- Has your child had any further assessment or been given any other diagnosis or support since your feedback appointment?
- What could the service have done differently to make the process better or easier for you and your child?
- If you could share one thing in particular with another family going through the same experience as you what would that be?

Appendix K

Example Section of a Transcript with Exploratory Coding

Example Transcript (All names or details have been altered for anonymity)

Emergent Themes	Original Transcript	Exploratory Comments
<p>Mums intuition</p> <p>Life long journey</p> <p>Uncertainty</p> <p>Difficulty describing differences</p> <p>Child is “different” – “not normal”</p> <p>Time frame / age</p> <p>Comparison to other children</p> <p>Number of differences</p> <p>Trying to manage the situation alone?</p> <p>Mums intuition</p>	<p><b>I: What brought you to want the assessment?</b></p> <p>P: Well I noticed something about James when he was 9months old. I knew that there was something...I hate using the word different or not normal but it’s the only language I’ve got to described it, you know. I just knew that he just wasn’t the same as other children. Hmm couldn’t communicate, hmm as time went on, no speech from him. If I ever went out anywhere he would just cling to my side, not leave me, he wouldn’t mix with other children. Hmm he started play group and he would just sit by the window with his teddy and his dummy and just stare out of the window and that’s all he would do. It took him weeks and weeks and weeks to sort of get into where the children were but even then he would play alongside, but he wouldn’t be directly involved with the children himself. Hmm and as time was going on his aggression was getting worse. He would just have these awful outbursts where he would destroy things, smash the inside of my car to bits. He’d smash his room to bits. He’d wake up at 2 or 3 o’clock in the morning in a rage. I’d have to hold him till he wore himself out. So I knew that...actually, I know he’s my first baby but something’s not right here.</p>	<p><b>Exploratory Comments</b></p> <p>Descriptive Comments: focus on describing the content of what the participant has said, the subject of the talk within the transcript (normal text).</p> <p><i>Linguistic Comments:</i> Focus on exploring the specific use of language by the participant (<i>italic</i>).</p> <p><u>Conceptual Comments:</u> Focus on engaging at an interrogative and conceptual level (<u>underlined</u>).</p> <p>Mums first concerns age 9months. <u>Reflect life long journey. Perception that he has always been a child who required help.</u></p> <p><u>Unsure what words to use? Feels restricted – uncertainty (sense that she hasn’t been given guidance on this)</u></p> <p><i>Hate – strong word.</i></p> <p><i>Different to others – not normal.</i> Physical and developmental differences described <u>emphasising that he is different?</u></p> <p><i>You know – seeking reassurance / confirmation.</i></p> <p>Not meeting expected milestones. Time / age. Starting nursery – difficulties became apparent. <u>Expected? Shock? Disappointment that her intuitive thoughts were confirmed?</u></p> <p>Listing differences – comparison with other children’s development / social skills.</p> <p><i>Repetition – weeks and weeks and weeks – emphasis, sense of a long time, longer than expected.</i></p> <p>Situation getting worse. Aggression. <u>Severity of situation.</u></p> <p>Outbursts – <u>impact of this on mum, the family home / belongings.</u></p> <p><u>Have to hold him - contain him – sense that she didn’t know what else she could do – powerless? Trying to handle it alone? Particularly with not knowing the cause of the rage.</u></p> <p><u>Mums intuition</u> despite James being her first baby.</p>

<p>Impact on mum</p> <p>Alone</p> <p>Determination</p> <p>Importance of support /recognition from others</p>	<p><b>I: How was it for you when you first picked up on those things?</b></p> <p>P: It's difficult to explain really. It was awful. Yes. But all I could focus on was right what could I do to help him really. So once the school had agreed that actually you know I think we need contact someone, it was more of a relief than anything, cos I thought well right at least you know, I on my way to getting him the help that he needs.</p>	<p><i>Use of the word 'I' suggest she felt alone / responsible.</i></p> <p><i>Awful –sense of emotional impact on mum in recognising James' difficulties, but empowered by how she could help him?</i></p> <p><i>Agreed – sense of now being shared? – she wasn't the only one.</i></p> <p><i>Relief – at the prospect of getting help/support or that someone else had recognised what she was seeing – confirmation, sense of feeling heard / believed.</i></p> <p><i>She felt more hopeful as managing the situation alone and feeling helpless was taken away.</i></p>
<p>Child as different</p>	<p><b>I: Can you tell me about more about how that was for you?</b></p> <p>P: So from 9 months you know his aggression and everything was getting worse and worse. Erm at play group this was when he would just kind of sit there and stare out of the window, but when he went over to nursery he used to...anything that had a string on it he would pick up and swing it and watch it, rather than anything that was going on in the classroom, that would be 'his thing'. He would get animals out and sort them out into groups and stuff. He just wasn't where he should be with the other children. He wasn't communicating with the other children. On the basis that he couldn't, he couldn't string a sentence together at that point. So he was really really struggling at that point.</p>	<p>Between 9months and going to school – things deteriorated.</p> <p><i>Repetition – worse.</i></p> <p><i>Description of difficulties.</i></p> <p><i>'His thing' – sense of difference from the other children.</i></p> <p><i>Just – emphasis of lack of skills</i></p> <p><i>Comparison with other children – confirmation to mum that he was different?</i></p>
<p>Comparison to other children</p> <p>Struggle</p> <p>Emphasising difference</p>	<p><b>I: And how did that feel for you as a parent?</b></p> <p>P: Horrendous. Horrendous. I felt helpless. You know. As his mother, I should be able to help him and I couldn't. I couldn't take it away from him. Whatever it was I couldn't take it away from him. I couldn't help him.</p>	<p>Developmentally he was delayed – <u>he was struggling vs mum was struggling?</u></p> <p>At that point – <u>has this changed now? Better? Worse?</u></p>
<p>Strong emotional impact on mum – helpless</p> <p>Wanting to remove the difficulties</p>	<p><b>I: Were other people helpful around that time. Did you get any support?</b></p> <p>P: Only from my mum. My husband was in denial for a lot of the time. 'Oh he will grow out of it, it's nothing to worry about, he's just</p>	<p>Strong emotional impact on mum. <i>Helpless, felt horrendous.</i></p> <p><i>Mums sense of 'should' – sense that being a mother means you 'should' be able to solve everything, protect your child from everything – feeling like a failure – that she couldn't meet his needs?</i></p> <p><i>Repetition – powerful emphasis.</i></p> <p><i>Use of of the word 'I' Guilt? Helplessness? Responsibility? feeling like a failure?</i></p>
<p>Impact on self (criticism)</p> <p>Alone</p>	<p><b>I: Were other people helpful around that time. Did you get any support?</b></p> <p>P: Only from my mum. My husband was in denial for a lot of the time. 'Oh he will grow out of it, it's nothing to worry about, he's just</p>	<p>Her mother was supportive. Husband and father in denial – impact of stigma? – <u>Stigma = rejection from others = loneliness? / lack of acceptance?</u></p> <p><u>Sense that you have to be a mother / have mother's intuition to understand.</u></p>

<p>Systemic impact</p> <p>Difference in parent opinion – alone?</p> <p>Paranoia/perceived judgment</p> <p>Determined</p> <p>Emotional impact</p> <p>Relief</p>	<p>a naughty boy.’ Hmm and my dad was very much the same as well, it was like, almost like they didn’t want a stigma. Really really difficult, cos I knew... so erm the fact the school had said ‘you know actually we need to something here’. At that point he kind of sat back and realised ‘oh actually ok maybe there is and things kind of...that was the turning point, cos I just felt like people saw me as this fussy mother, you know, which at the time I never really thought about it cos I was so focused on James but to not have the support from my husband it was hard. It was hard at the start.</p> <p>I: Was it helpful when others started to notice? P: Yeah. It was helpful... [long pause]</p> <p>I: They can be difficult feelings to sit with... P: Yeah really difficult cos originally I didn’t think I would be able to have children. It was three years it was before we had James. It took us three years, so you know when I finally had him it was just you know... I’d finally got what I wanted so it was a whole mix of emotions going on there really.</p> <p>I: So when was it that other people first noticed? Was it the nursery teachers you mentioned? P: Well it actually went back to playgroup cos you know when he was just sitting there and not joining in and they would do little assessments and erm, he couldn’t recognise shapes, or numbers or those kind of things. They kind of said to us ‘look this is what we’ve seen...I don’t know whether you want to speak to the health visitor about it’, which he did. We took him along...he got an appointment with...it was Dr. Guy* but it was up to the...originally we went to our own GP you know just to say that I had concerns and they made us an</p>	<p><u>Impact of not having your husband support? Feeling alone? Increased pressure on whether to share your concerns further? – could she has felt blame for the stigma? Unsupported? ‘Really’ repetition – to emphasise extend of the difficulty.</u> <u>“I knew” – sense of responsibility</u> <u>mum intuition – high sense of responsibility – going against husband’s thoughts to get support for child – putting the child first. Feeling lone?</u></p> <p><u>Saw me as this ‘fussy mother’ – paranoia? Impact of how she feels other see her / judge her / sense that at the time this wasn’t important because of the focus she had on doing what she felt needed to be done in terms of accessing support.</u> <u>Sense of focus = determination.</u></p> <p><u>Relief?</u> <u>Pause: reflection? Emphasis of the difficulty in talking about this?</u></p> <p><u>Added context. Didn’t think they would be able to conceive. Longed for child. Heightened sense of importance to get it right maybe? Being able to conceive was a gift, a miracle?</u></p> <p>Mixed emotions.</p> <p>Reflection.</p> <p><u>Went back to – sense of took a long time. Started at an early age.</u></p> <p><u>Nursery did some assessments and noticed developmentally not where he should be – advised contact with health visitor.</u></p> <p><u>Followed advice compliance - Contacted health visitor.</u> <u>Professional ambivalence so left up to parents? Parents responsibility? Impact on parents? GP &gt; health visitor</u></p> <p><u>Originally – perhaps emphasises number of appointments / longevity of the process.</u></p>
<p>Long awaited child = mixed emotions – sense of have to manage / get it right.</p> <p>Long journey</p> <p>Advise by others to seek help – parents responsibility</p> <p>Listing difficulties</p>		



<p>Not heard/listened to – impact on self</p>	<p>appointment to see Dr. Guy, and that was at a health clinic in [local area]. Hmm and it was just...I was so angry when I came out of there because she had this piece of paper on a clip board which she never never took her eyes off. She got James to do a jigsaw puzzle, asked a few questions and basically said ‘nothing wrong with him’ to which point I had to get out of the room, because if I didn’t leave I was really scared of what I was going to do and I came out of there really upset.</p>	<p><i>Angry – strong emotions, pauses / hesitation to emphasise this.</i></p> <p><i>Not heard/listened to – <u>impact of professionals lack of thorough assessment / invalidating / dismissive.</u></i></p> <p><i>Anger. Had to get out otherwise scared of what she would do – <u>heightened sense of impact at the situation – can’t be responsible for own actions.</u></i></p> <p><i><u>What would people think of her if she displayed those emotions in the room?</u></i></p> <p><i><u>Mixed emotions.</u></i></p>
<p>Strong emotions – angry at professionals</p>	<p><i>I: How did you process that after the assessment?</i></p> <p>P: I don’t think I’ve ever really processed it to be honest. It’s still something that really eats away at me and as it happens when we finally did get the school to get the ball rolling, it was Dr. Guy who saw him again.</p>	<p>Lack of closure from that appointment. Ongoing impact on her? Does she wish she had challenged it there and then rather than getting out of the room?</p> <p><i>Eats away at her – metaphor - <u>regret? – impact on self?</u></i></p> <p>Future impact on trust and interaction with professionals.</p>
<p>Lack of closure</p> <p>Regret? Lasting impact of professionals</p>	<p><i>I: How was it seeing the same person again?</i></p> <p>P: I was like ‘oh God no please’ and it was more of the same thing...looked at her clip board and asked a few questions and James was actually being a nightmare. I was like ‘can you not see this?’ hmm and I’m not sure what happened after that. I’m a bit fuzzy about what happened from there. It must have been the schools input. I think it must have been, cos its all really really fuzzy, cause at that point I had a young baby as well, so I really apologise for my memory.</p>	<p><u>Fear of history repeating itself?</u></p> <p><u>Again invalidated – not heard, lack of observation.</u></p> <p><u>Desperation, helplessness, despair?</u></p> <p><i>Nightmare – emphasis of severity of his behaviours / differences. <u>Sense of shock as to why professional had different opinions. Stuckness between health and education.</u></i></p> <p>Unable to remember details. <u>Consciously blocked them out?</u></p> <p>Apologetic – pleasing interviewer?</p>
<p>Impacting of seeing the same professionals</p> <p>Helplessness, despair?</p>	<p><i>I: Don’t worry it’s a long time ago.</i></p> <p>P: It is a really long time ago, a lots happened. I still, that’s the thing I remember the most from it, the anger that I was feeling at the time.</p>	<p>The anger is the strongest memory. <u>Emotional impact on mum – emphasised by the fact that this has stayed with her despite being a number of years ago.</u></p>
<p>Emotional impact on mum</p> <p>Long process.</p>	<p><i>I: And he was quite little wasn’t it.</i></p> <p>P: Yeah he was about 3. When he was assessed he was in reception so he was actually 4 when he was first assessed. Yeah.</p>	<p>Parent talking about the first time her son was assessed at this point in the interview. He had since undergone a recent assessment.</p> <p>Assessment started age 3-4. (Since been reassessed).</p>

<p>Regret at not asking more questions during the feedback – long standing impact on mum (self-criticism) – ‘should’ have done more.</p> <p>Power of services?</p> <p>Lack of service provision.</p> <p>Emotional impact Regret (lost the ‘battle’) Anger. ‘should’ – self criticism Self development and growth</p> <p>Ongoing process – long – uncertainty – lack of closure</p> <p>Internal conflict – relief at outcome vs sense of outcome not being right</p> <p>Power of professionals – you have to trust them</p>	<p><b>I: What was it like hearing the outcome of the assessment?</b></p> <p>P: When he had the actual autism assessment, obviously they had to go and write, you know, the reports and that. This wasn’t Dr. Guy by the way, this was someone else who did the actual assessment. So when all that, got all the information together and she came to the house to talk us through it. hmm an I’m still kicking myself now for not having the right questions ready. Cos I was told that he was...he was just borderline, but what she’d done is that she’d scored him just under because there was that many limited places in CAMHS that they didn’t feel that they really had enough time to give him that diagnosis.</p> <p><b>I: How was that as a parent?</b></p> <p>P: Really hard. But...at the time...erm suffering from depression, young baby, er a child...clearly something wrong. I’m angry now because I should have been stronger. I feel like I should have fought harder because she said to me were going to leave his case open for 18months because it could, it could er...start up when he gets a little bit older, and then I thought well if your telling me that symptoms might not show until a bit older then surely this assessment is kind of irrelevant. Because you don’t know what’s gonna, you know happen in the next 18months. But at the time everything was so jumbled and hmm...I had all these emotions going on. One side of me was kind of saying right well, there’s nothing wrong so that’s good lets just you know...the other side was like no this isn’t right! this isn’t right! So it was really really difficult for me at that time and obviously being my first baby and never going through anything like this before, you kind of have to say to yourself well they’re professionals so you’ve got to, you’ve got to put a bit of faith in them.</p>	<p><u>Sense that they had to wait for the outcome. Long process.</u></p> <p>Process and impact of not getting the diagnosis – the feedback appointment and report. <u>Specified that this assessment was done by another professional. Lasting impact on mum.</u></p> <p><u>‘I’m still kicking myself now’ – strong sense of longstanding regret. Has this fuelled mums continued determination to get the right support and wanting further assessments.</u></p> <p>Told he was borderline. <u>Seems this terminology might have been unhelpful?</u> <u>Use of the word ‘just’ – added insult?</u> <u>Uncertainty? – sense that the only reason he didn’t have the diagnosis confirmed was because of lack of service availability / provision? – fuelled mums anger at services?</u></p> <p>Mum reflecting on the outcome at a time when she had depression. <u>Lots of hesitation, struggling to get sentence out. – sense of reflection, still working through how she felt about this? - maybe some resurgence of the emotion.</u> <u>Regret? Reflection? Criticism? Sense of ‘should’ – reflection on personal self growth and development now – stronger person.</u></p> <p><u>‘fought’ – sense of battle.</u></p> <p><u>No certainty given – case left open for 18months – longevity of process – lack of closure.</u></p> <p>Uncertainty about the future– <u>felt left? Abandoned for 18months?</u> <u>Raised voice ‘this isn’t right’ – annoyed, regret, convincing self/researcher?</u> <u>Everything was jumbled – overwhelming?</u></p> <p><u>Internal conflict – relief at outcome vs sense of outcome not being right</u></p> <p>First baby – <u>sense that you ‘have’ to trust professionals. Professionals are powerful? This being the ‘right’ thing to do – but at the same time deep down not believing this (e.g. a bit of faith in them)</u></p>
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<p>Multiple professionals</p>	<p>I: Do you feel like you had that faith?  P: I thought I did. Until things got worse with him.</p> <p>I: So that was the start of the autism assessment?  P: Yeah.</p> <p>I: And it was the schools suggestion to go for that initially?  P: Yeah, a mixture, school, GP, myself. Yeah.</p>	<p><u>Uncertainty – change of perspective when things deteriorated.</u></p> <p>Lots of people involved. <u>Where did mum fit into this?</u></p>
<p>Relief</p>	<p>I: So when they said it was borderline, and they'd keep it open for 18months. How was that 18months?  P: Well initially I thought well maybe it is the right decision cause initially he did improve with his reading and his writing and his communication. I put that down to the school though. They have been absolutely bloody amazing with him all the way through. I couldn't have asked for anything better erm from them. Each and every teacher that he's had, they've bonded with him, they've had this really special relationship with him. Hmm because he is so kind and sensitive and anyone that meets James just loves him (laughs). They do, and it's so nice to hear that with all that he's going through, you know that actually...he's a good boy. So yeah that was all going quite well and then he was, you know moving up through to the next year and that's behind and not coping in class, academically, and with his peers as well. Couldn't kind of make those bonds, you know, still kind of playing alongside you know but not with. Even thought they all really you know, like James. Every single person in his class likes him, he just can't kind of you know, cos you have groups that break off and that don't you, but he just can't, he's always on his own. Well I say on his own he's got a friend Sam* who has been diagnosed with sever autism and</p>	<p>Relief?</p> <p>Fluctuating presentation. <u>Sense that maybe it was the right decision. Ambivalence?</u></p>
<p>Fluctuations in presentation</p>	<p>P: Well initially I thought well maybe it is the right decision cause initially he did improve with his reading and his writing and his communication. I put that down to the school though. They have been absolutely bloody amazing with him all the way through. I couldn't have asked for anything better erm from them. Each and every teacher that he's had, they've bonded with him, they've had this really special relationship with him. Hmm because he is so kind and sensitive and anyone that meets James just loves him (laughs). They do, and it's so nice to hear that with all that he's going through, you know that actually...he's a good boy. So yeah that was all going quite well and then he was, you know moving up through to the next year and that's behind and not coping in class, academically, and with his peers as well. Couldn't kind of make those bonds, you know, still kind of playing alongside you know but not with. Even thought they all really you know, like James. Every single person in his class likes him, he just can't kind of you know, cos you have groups that break off and that don't you, but he just can't, he's always on his own. Well I say on his own he's got a friend Sam* who has been diagnosed with sever autism and</p>	<p>Pleased with school support. <u>Sense that she couldn't have done it without schools support and input.</u>  <u>Bonded with him/special relationship – words that may typically be used to describe mother-son relationship?</u>  <u>sense that he's different, needs this extra support.</u></p>
<p>Celebrating his personality</p>	<p>P: Well initially I thought well maybe it is the right decision cause initially he did improve with his reading and his writing and his communication. I put that down to the school though. They have been absolutely bloody amazing with him all the way through. I couldn't have asked for anything better erm from them. Each and every teacher that he's had, they've bonded with him, they've had this really special relationship with him. Hmm because he is so kind and sensitive and anyone that meets James just loves him (laughs). They do, and it's so nice to hear that with all that he's going through, you know that actually...he's a good boy. So yeah that was all going quite well and then he was, you know moving up through to the next year and that's behind and not coping in class, academically, and with his peers as well. Couldn't kind of make those bonds, you know, still kind of playing alongside you know but not with. Even thought they all really you know, like James. Every single person in his class likes him, he just can't kind of you know, cos you have groups that break off and that don't you, but he just can't, he's always on his own. Well I say on his own he's got a friend Sam* who has been diagnosed with sever autism and</p>	<p>Teachers and school have been very helpful and supportive. All love James. <u>Sense of pride in mum.</u></p>
<p>Comparison to others – delayed – behind – sense of difference</p>	<p>P: Well initially I thought well maybe it is the right decision cause initially he did improve with his reading and his writing and his communication. I put that down to the school though. They have been absolutely bloody amazing with him all the way through. I couldn't have asked for anything better erm from them. Each and every teacher that he's had, they've bonded with him, they've had this really special relationship with him. Hmm because he is so kind and sensitive and anyone that meets James just loves him (laughs). They do, and it's so nice to hear that with all that he's going through, you know that actually...he's a good boy. So yeah that was all going quite well and then he was, you know moving up through to the next year and that's behind and not coping in class, academically, and with his peers as well. Couldn't kind of make those bonds, you know, still kind of playing alongside you know but not with. Even thought they all really you know, like James. Every single person in his class likes him, he just can't kind of you know, cos you have groups that break off and that don't you, but he just can't, he's always on his own. Well I say on his own he's got a friend Sam* who has been diagnosed with sever autism and</p>	<p><u>'With all that's he's going through' – sense of big impact on James / the family, difficult process. He's a good boy – confirmation? Interesting use of language – is this mum compensating for the possible stigma that autism would mean he is naughty? Sense of mum's clarification that he can't control his behaviour difficulties</u></p>
<p>Emphasising differences compared to other children</p>	<p>P: Well initially I thought well maybe it is the right decision cause initially he did improve with his reading and his writing and his communication. I put that down to the school though. They have been absolutely bloody amazing with him all the way through. I couldn't have asked for anything better erm from them. Each and every teacher that he's had, they've bonded with him, they've had this really special relationship with him. Hmm because he is so kind and sensitive and anyone that meets James just loves him (laughs). They do, and it's so nice to hear that with all that he's going through, you know that actually...he's a good boy. So yeah that was all going quite well and then he was, you know moving up through to the next year and that's behind and not coping in class, academically, and with his peers as well. Couldn't kind of make those bonds, you know, still kind of playing alongside you know but not with. Even thought they all really you know, like James. Every single person in his class likes him, he just can't kind of you know, cos you have groups that break off and that don't you, but he just can't, he's always on his own. Well I say on his own he's got a friend Sam* who has been diagnosed with sever autism and</p>	<p><u>Physical descriptions used for emphasis. E.g. down hill. Sense that its hard to get back up, a struggle, a battle.</u></p> <p>Strong sense that he is liked by others – <u>repetition of this – does this highlight how important it is for mum knowing that he is liked (despite his differences?), acceptance? You know – repetition – sense of seeking clarification, ensuring interviewer following her story (? importance of being heard)</u>  James' alone – Listing difficulties / differences compared to other children.</p>

<p>Comparison of child to another child with diagnosis 'so he must have it'</p>	<p>ADHD and they click. So they kind of look after each other, which is lovely to see.</p>	<p><u>Sense that he is similar to his friend who has a diagnosis they click – so 'James must have a diagnosis'? Does observing their similarities cause mum more confusion as to why James was not diagnosed?</u></p>
<p>Alone Powerless / helpless at not being able to protect child from being lonely</p>	<p><b>I: How does that feel when you see him on his own?</b> P: It's horrendous, to think that he might be lonely. Because when I drop him off at school well I can't do anything then. I'm not there. I'm not in control of him. (sigh). Your heart just kind of sinks every time you drop him off at school.</p>	<p><u>Strong feelings / worry that James is lonely. Feeling that she is unable to protect him from this at school. – does this reflect mum's loneliness?</u> <i>"I" – mum feels responsible. Losing control.</i> <u>Impact of this on mum – unable to take responsibility for this as she recognises she cant be with him all the time – guilt?</u> <i>Heart sinks – physical descriptions used for emphasis.</i></p>
<p>Celebrating friendship</p>	<p><b>I: Has that changed at all as he has got older?</b> P: No cause he's still struggling. In fact...it's even worse now.</p>	<p>Situation is worse now. Continued struggle. Battle.</p>
<p>Shared identify Relief</p>	<p><b>I: And the flip side of that, how do you feel when he's with Sam? Does that change your feelings?</b> P: Yeah. [sighs - laughs]. I love the fact that their funny. They are funny together, but even now and then when ones in a bad mood, they are just like brothers, they fight, fight like hell. Then five minutes later they're like are 'alright bud?' they are really really funny to watch. They are like an old married couple, that's how me and my friend describe them. So it's nice because they've had this kind of relationship since they were about 3 years old, that's when it first started. So it makes me feel good that he's always going to have that person in his life who knows actually he's kind of thinking, he knows what he's going through, he knows his thought process.</p>	<p><i>Sighs / laughs – expression of relief?</i>  Pleased that he has one friend who understands him. <i>Mums delight at this. Sense that she knows what it feels like to be alone and this is unpleasant.</i>  <u>Importance/value of shared identify/experiences.</u> <u>Powerful impact of friendship. Sense that having that one friends who understands him and see the world as he see's it takes some pressure from mum. Eases mum's pain? Feels guilty about this but comforted by the boy's friendship knowing someone understands him even though she wishes it were her.</u> Friendships – normality in life – this is why its so important he has this one friend? <i>Kind of relationship – unique to people who are a bit different?</i> <u>Sense of difference. Only a person with autism can understand him – sense that this means he must also have autism?</u></p>
<p>Importance of shared identify for the child and the mum.</p>	<p><b>I: Do you feel in the process you've had someone like that, who you've been able to share your thoughts or concerns with?</b> P: Oh yeah, Sam's mum she's my best friend in the world. That's the one positive thing that comes out of it. She's like my sister so we're never apart. Crying on each other shoulder all the time. So it's nice to</p>	<p><i>First started – longevity.</i>  Positive aspect of situation – friendships with other mums. <u>Only those in the same situation understand</u>  Strong support from another mum in the same situation '<i>best friends, sisters</i>'</p>

<p>Situation is all consuming overwhelming, emotional journey</p> <p>Impact on mum</p> <p>Professionals conflicting messages Mum in the middle - powerless</p> <p>Hopeless, helpless</p> <p>Mums losing control</p> <p>Impact on school observation on a good day = Mum's doubt in outcome – Lack of closure</p> <p>School observation = barrier to outcome.</p>	<p>have that release. Even when there isn't anything particular wrong, some days we will just turn up at each others house and cry for no reason (laughs) just because we can. You know, which is nice.</p> <p><b>I: It sounds important to have that support.</b></p> <p>P: Yeah. Definitely.</p> <p><b>I: What it is like for you now?</b></p> <p>P: It is upsetting now because I've asked for him to have another assessment because I can still see that something's not right. His teachers have told me they can't understand why he hasn't been given a diagnosis because they can quite clearly see that there's something... [sigh] that he's on the spectrum. Hmm so to be told again that actually were not going to give him another assessment...but then I was here again last Friday for an emergency appointment with Dave* [ND clinician] because he was sobbing his heart out in the morning telling me that he couldn't open up to me cos he needed to speak to Dave and he's terrified about these episodes that he's having where he's zoning out, he's losing time. Now I can lose him for an hour and he's got no idea what's going on at that point. He's just blank stare. And he's struggling again in the classroom. When they went out to do his classroom assessment at the start of the year [sigh] they went on a day where it was his favorite subject. It was about insects. So of course he was absolutely enthralled. So as far as the assessment went, you know...there was nothing to show cos he was complying.</p> <p><b>I: Do you feel that hindered the process?</b></p> <p>P: Absolutely. I really do.</p> <p><b>I: Do you think there is anything that hindered the process?</b></p>	<p><u>sense of closeness as you can only understand / appreciate if you are in that situation together. Shared identity.</u></p> <p>Cry for no reason: <u>Sense of how much impact this has – all consuming – overwhelming – even when there is nothing specific still want to cry at the situation as a whole</u></p> <p><u>“Because we can” – sense that this is something that she can control; whereas many other elements in this process she can't.</u></p> <p>Wanting another assessment. <u>Hope of difference outcome? Hope that the system was wrong?</u></p> <p>Conflict between school and health services opinion – <u>mum stuck in the middle?</u></p> <p><u>Teachers referring to him as being ‘quite clearly’ on the spectrum – impact of this on mum when she has been told he is not? sense professionals must blind?</u></p> <p>Emergency appointment – <u>crisis?</u></p> <p><i>Physical description for emphasis of her son's emotional pain.</i></p> <p>Positive response from service.</p> <p><u>Sense of confusion, she doesn't understand what is going on and this is difficult to manage.</u></p> <p><i>Lose him – sense of losing him not just in an absence but losing him in general? – <u>feeling like she's lost control.</u></i></p> <p><i>Struggling again – reoccurring, round in circles. <u>A never ending Battle?</u></i></p> <p>School observation as part of the assessment - done on a day that he was engaged in a subject of interest. – <u>sense that saw him on a good day so this influenced the outcome. Doubt that the outcome is right. <i>Laughs -? disbelief, sense of her perception that the situation is a joke.</i></u></p> <p><u>Noting to show– sense you have to look harder or at the right time. Contradiction to physical and develop differences emphasised previously.</u></p> <p>One school observation and on a good day – hindered the process.</p>
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<p>Battle – mums fight not James’</p> <p>Impact of the fight/battle on mum</p> <p>systemic impact on family / siblings.</p> <p>Hope / emphasis on re-assessment</p> <p>Lack of closure</p> <p>Inadequate service</p> <p>Stuck between services</p> <p>Enmeshed? Assessment is for mum not child?</p> <p>Lack of closure – hope of future assessment</p> <p>Future hope</p> <p>Judgment/Paranoia?</p>	<p>P: I feel like I’ve been fighting all the way.</p> <p><b>I: How is that fighting?</b></p> <p>P: Exhausting. I’m exhausted. Especially with having 3 other children as well, who all need attention too. It is, it’s exhausting...I just...if they did another assessment on him and you know still that came back that actually you know he’s still borderline. You know that’s ok. But it’s the fact that you know I can see it, but they’ve just got a half an hour snap shot out of his life and based it on that.</p> <p><b>I: How does that feel thinking that that the only bit they based the outcome on.</b></p> <p>P: It’s not good enough, that’s how I feel, it’s not good enough</p> <p><b>I: Have you felt able to say that to professionals?</b></p> <p>P: I haven’t had a chance yet, no. I, um, Dave...he is going to phone the school cos school wanted to speak to him, and I’m going to go in this week to have a chat with his teacher, cos I don’t know if I’ll get anywhere but I really want to have him assessed again. I need it.</p> <p><b>I: What do you hope to get from the assessment this time?</b></p> <p>P: Well like I say whether it’s... because he’s that bit older, I think from the assessment we’d have a clearer picture.... For him. And even if it did come back, well actually he’s still only borderline, well that’s ok cause I can work with that. It’s the fact that...you know to be told no, when I know... I know! (sigh) he needs it. I know he does. I’m his mum. I know. I’m not an overbearing mother. I know.</p> <p><b>I: You mentioned earlier that it was sometimes hard to share those feelings. Do you still feel like that when talking to professionals?</b></p>	<p>Battle. <i>Use of “I’ve” first person – <u>this is mums battle – not James’</u>. Responsibility is on mum.</i></p> <p>Impact of this fight. Exhausted. Battle – defeated?</p> <p>Wider impact on family – siblings – mum trying to divide attention. Impact of this – <u>guilt?</u></p> <p><u>Putting a lot of emphasis / hope on having another assessment. Sense that as long as an assessment is given it will give some answers and regardless of the outcome that feels ok – but without that there is lack of closure everything is still uncertain. ?why mums feels a third assessment would be any different? ? implications for previous lack of trust in professionals, bad experiences of feeling heard or lack of explanations regarding why he did not meet the diagnostic criteria.</u></p> <p>Snap shot of observation blamed for outcome. <u>Unfair, unjust?</u></p> <p>Service not good enough. <u>Sense of being let down.</u></p> <p><u>Stuck between health professionals and school.</u></p> <p><i>Use of ‘I’ – mums needs the reassessment for her. Is this because she felt she ‘should have fought’ harder during the last assessment. <u>Enmeshed?</u></i></p> <p><i>Want the assessment &gt; changed to <u>NEED the assessment. <u>Lack of closure.</u></u></i></p> <p>As he gets older you see will it more? It’s more developed? Worse?</p> <p><i>Change of perspective again – previously assessment was for mum now she has switched back to the assessment being for James.</i></p> <p>Mum searching for a ‘workable’ explanation? <u>Searching for an answer that she can accept – work with – sense that he will get diagnosis in future.</u></p> <p><i>Repetition of “I know” – strong emphasis. <u>Determination – mums knows best.</u></i></p> <p><i>Clarification I’m not an overbearing mother – <u>worried about other perceptions? Paranoia.</u></i></p>
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<p>Determination. Mums knows best.</p>	<p>P: That they don't understand me. Um not with Dave. He's a nurse here and er I get the feeling that he gets it and he's trying to find loads of solutions or answers to questions erm and he took James' case back to board for me. Um but I don't see how...I don't know what happens in this board, whether you know it's just a group of people sitting around a table looking at a few pieces of paper. You know let me speak to the board. Why can't I speak to them?</p>	<p>They don't understand – <u>impact of not feel heard</u>.  <u>Sense that nurse would understand because this is a medical disorder?</u>                  Importance of feeling like someone is one your side – shared fight.</p>
<p>Impact of others opinions</p>	<p><i>I: Do you feel that would be important?</i></p>	<p>Power of the board – professionals. (sitting / few pieces of paper – <u>minimises decision</u>)  <u>sense that mum feels the decision was taken too lightly</u>)  <i>Don't know what happens – confusion, uncertainty, lack of information</i>  <u>Powerless. Not heard. No control. Impact on mum.</u></p>
<p>Power of the board</p>	<p>P: Yeah. Listen to me. This has been going on now for 6 years. Nearly 7. So please, you know, can I, can you...can you...sit down and listen to me. Let me tell you about it.</p>	<p>Long process 6-7years!                  Mums wants her say – <u>Did not feel heard previously / renewed determination perhaps because she felt like she wasn't in the right place to do this before due to her depression etc?</u> <u>Sense that sharing her thoughts would help/change the outcome – she needs to have the opportunity to prove that he has autism?</u>  <i>Please (hesitation/repetition)- <u>begging/pleading</u>.</i></p>
<p>Powerless.</p>	<p><i>I: How have your feelings changed? You talked a bit about that fight initially, can you tell me a little bit more about that and whether that's changed as times gone on.</i></p>	<p>Internal fight got stronger now. <u>Personal growth, determination</u>. Not scared anymore.</p>
<p>Long process</p>	<p>P: Yeah. In terms of that, that...that fight inside me...that's got stronger now. I'm not scared to do it.</p>	<p>Fight is stronger now. <u>James has confirmed her thoughts now he is verbal / can share things with mum – is this what has given her the strength to fight? Before she was unsure, based actions on her own intuition. Confirmation from James.</u>  <i>Use of metaphor – take a bullet for him / die for him – mum is very clear on her priorities.</i></p>
<p>Mum silenced – determined to fight.</p>	<p><i>I: What do you think change is about?</i></p>	<p>Her children are her world.</p>
<p>Fight. Personal growth and determination.</p>	<p>P: Because now that James has got older, he can tell me, he's started to try and express him emotions. And erm as a... as a mum hearing that... this is my baby and this is the way he's feeling... well you'd die for them. You'd take a bullet for them so... this is nothing compared to, you know, the feelings that I...that I have for him. Standing up in front of a room full of people, I'd do it any day of the week if I thought that'd help him. That fight will always be there...for any of them.</p>	<p><i>Use of the word baby – the most important thing to her – fight whoever to get him support / protect him / his needs.</i></p>
<p>Wanting to take this away from him – protect him – fight for him</p>	<p></p>	<p><u>Sense of it being mum 'vs' a room full of people</u>  <u>Sense of determination – she will do whatever it takes, she will win the battle.</u></p>

## Appendix L

### Summary of Emergent, Sub and Superordinate Themes

Emergent Themes	Subthemes	Superordinate Themes
<ul style="list-style-type: none"> <li>⇒ Highlighting multiple differences</li> <li>⇒ Comparison to typically developing peers</li> <li>⇒ Comparison to siblings</li> <li>⇒ Comparison to children with Autism Spectrum Disorder diagnosis</li> <li>⇒ Parents intuition</li> <li>⇒ Parent knows best</li> <li>⇒ Unwanted differences</li> </ul>	Emphasising Difference	<b>“My Child is Different”</b>
<ul style="list-style-type: none"> <li>⇒ Uncertainty in describing differences</li> <li>⇒ Impact of no legitimate label</li> <li>⇒ Lack of evidence</li> <li>⇒ Highlighting vs minimising differences</li> <li>⇒ Explaining difference to the child</li> <li>⇒ Language used to describe difference</li> </ul>	Talking about and Disclosing Difference	
<ul style="list-style-type: none"> <li>⇒ Acceptance</li> <li>⇒ Difference is personality</li> <li>⇒ Difference makes the child way they are</li> </ul>	Celebrating Difference	
<ul style="list-style-type: none"> <li>⇒ Isolation</li> <li>⇒ Marginalised by others</li> <li>⇒ Unsupported by family/professionals</li> <li>⇒ Service as powerful</li> <li>⇒ Parent as powerless</li> <li>⇒ Lack of support</li> <li>⇒ The value of shared identity</li> </ul>	Alone	<b>The Emotional and Psychological Journey</b>
<ul style="list-style-type: none"> <li>⇒ Impact of public perceptions</li> <li>⇒ Importance of validation/being heard/listened to</li> <li>⇒ Parental / Family conflict</li> <li>⇒ Self-doubt</li> <li>⇒ Searching for concrete evidence</li> <li>⇒ School observation on a “good day”</li> </ul>	Judged	
<ul style="list-style-type: none"> <li>⇒ Multifaceted role of the parent</li> <li>⇒ Parent as teacher (child &amp; others)</li> <li>⇒ Parent as therapist</li> <li>⇒ Parents as advocate and protector</li> <li>⇒ Being a detective</li> </ul>	Impact on self	



<ul style="list-style-type: none"> <li>⇒ Proving the case (Getting it right/remembering the right information)</li> <li>⇒ Managing the systemic impact</li> <li>⇒ Impact of the critical self</li> </ul>		
<ul style="list-style-type: none"> <li>⇒ Long waiting times</li> <li>⇒ Process as all consuming/life long</li> <li>⇒ Multiple professionals</li> <li>⇒ Lack of understanding from professionals</li> <li>⇒ Lack of support</li> <li>⇒ Service has the final say</li> <li>⇒ Impact of seeing the same professionals</li> <li>⇒ Desire to protect the child</li> <li>⇒ Enmeshed – (diagnosis for self or child?)</li> <li>⇒ Diagnosis as a badge</li> <li>⇒ Feeling determined</li> <li>⇒ Feeling powerless, stuck and exhausted</li> <li>⇒ Navigating health and education services (being stuck in the middle)</li> <li>⇒ Battle with critical self</li> <li>⇒ Personal growth and development</li> </ul>	<p><b>Unrelenting Battle</b></p>	
<ul style="list-style-type: none"> <li>⇒ Uncertainty, confusion and disbelief</li> <li>⇒ Disagreement with outcome</li> <li>⇒ Sense the outcome is not right</li> <li>⇒ Doubt: Outcome based on a “snapshot” of child’s life (brief school observation)</li> <li>⇒ The more people get to know child the more they will notice</li> <li>⇒ Needing time to process</li> <li>⇒ Idea that ASD will show in time</li> <li>⇒ The value of diagnosis (for help and support)</li> <li>⇒ Continued fight</li> <li>⇒ Feeling stuck</li> <li>⇒ Helpfulness of professional’s description regarding the outcome</li> <li>⇒ Value of having the door ‘left open’/‘a safety net’</li> <li>⇒ Service recommendation (Value of being offered a feedback appointment to discuss impact of outcome on self and family)</li> </ul>	<p><b>Lack of Closure</b></p>	<p><b>Understanding the Outcome</b></p>
<ul style="list-style-type: none"> <li>⇒ Trust in professionals</li> <li>⇒ Satisfaction that others were wrong</li> <li>⇒ Moving forward</li> <li>⇒ Hope</li> </ul>	<p><b>Relief</b></p>	

<ul style="list-style-type: none"><li>⇒ Continued search for explanations</li><li>⇒ Hope of second opinion in future</li><li>⇒ Acceptance</li><li>⇒ Fear</li><li>⇒ Uncertainty</li><li>⇒ Closed doors</li><li>⇒ Lack of support</li><li>⇒ Worries about transition</li><li>⇒ The ‘inevitable crisis’ will occur</li><li>⇒ Perception that service provision and resources are wasted if assessment isn’t continued – something is still not right</li></ul>	<p>The Future</p>	
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## Appendix M

### Summary of Superordinate and Sub Themes Relevant to Each Participant

	“My child <i>is</i> different”			The Emotional and Psychological Journey			Understanding the outcome			
	Emphasising Difference	Talking about and Disclosing Difference	Celebrating Difference	Alone	Judged	Impact on self	Unrelenting Battle	Lack of Closure	Relief	The Future
<b>Jane</b>	√	√	√	√	√	√	√	√	√	√
<b>Melissa</b>	√	√	√	√	√	√	√	√	√	√
<b>Martha</b>	√		√	√	√	√	√		√	√
<b>Emma</b>	√	√	√	√	√	√	√	√	√	√
<b>Vicky and Paul</b>	√	√	√	√	√	√	√	√		√
<b>Sarah</b>	√	√				√			√	√

## Appendix N

### Illustrative Quotes for Each Theme

Superordinate Themes	Subthemes	Example Quotes
<b>“My Child is Different”</b>	Emphasising Difference	<p>Jane: We see a lot [of professionals], cos he’s quite complex.</p> <p>Melissa: She’s now in the learning center, she doesn’t seem to fit in there, and we’ve tried her with [youth club name], which is a youth club and she doesn’t seem to fit there either, it’s like nowhere where she’s sort of fits and gels with people, so it’s quite difficult really.</p> <p>Martha: I wondered if he had something cos we have a nephew that has it and his mum had said to me that George was acting a bit like Samuel when he was his age, so that’s when we turned around and said I’m going to bring him to the doctor just to see.</p> <p>Emma: He would get animals out and sort them out into groups and stuff. He just wasn’t where he should be with the other children. He wasn’t communicating with the other children.</p> <p>Vicky: I’m not saying that he has got a very bad case of it cos he hasn’t, I’d say he is...he he has...he shows traits of it...my brother’s son had autism, has got autism, and he didn’t speak until about five years, so I know there is extreme cases. Charlie’s not like that, he’s not an extreme case, but he is...he does have the traits of it...I watch the programme The Undateables and there are sometimes some characters in that and I’ll go “that’s Charlie!”</p> <p>Paul: Yeah and having a brother the same age, there is ten months between them, you could see how one brother was coping compared to the other, you know seeing slightly different traits.</p> <p>Sarah: It’s hard cause if I say to his brother, what are you feeling? he would just come out with it, he’d say oh I’m happy or I’m worried about this or erm I was this, so he would just come out with it and say what was in his imagination, whereas Henry wouldn’t.</p>
	Talking about Disclosing Difference	<p>Jane: There is something non NT [neuro-typical] and I know that anyway, that’s not a shock and that’s perfectly fine and we will find out as he gets older wont we what that specifically is, if there a word for it.</p> <p>Melissa: I wasn’t really open with people. My friends got a little boy that’s got erm...has been diagnosed with Asperger’s and she’s very open to people and will say you know this is what he has difficulty with, and I think maybe because I didn’t have a diagnosis, I never sort of said to the other parents ‘well, she struggles with this’ or something you know so maybe I should of and maybe they would have been a bit more understanding.</p>

		<p>Emma: I noticed something about James when he was 9 months old. I knew that there was something...I hate using the word different or not normal but it's the only language I've got to described it, you know? I just knew that he just wasn't the same as other children.</p> <p>Vicky and <i>Paul</i>: There is something you know, but it's not me wanting to put a label on him cos far from it. I don't want...I don't want to think my son has like autism or like Asperger's, I don't want that to happen you know. So it's not like I'm one of these parents that's like 'oh he's got this or he's got that' cos I haven't even told him my concerns. <i>No</i>. He doesn't even have a clue why he's been coming here. He's like 'why do I have to go there?' cos I don't want to label him. I don't want to say 'well I think you've got this' cause' I don't want him to ever say in life 'I can't do that because I've got...this problem or that problem' do you know what I mean?</p> <p>Sarah: I think that erm, you know his reality of things is probably a bit different.</p>
	<p>Celebrating Difference</p>	<p>Jane: He's always going to be quirky and long may he rein! Good for him!</p> <p>Melissa: I suppose sometimes because she had her own bit of personality I'd find it quite amusing, you know and I'd think oh that's quirky.</p> <p>Martha: We do know that he is intelligent because God he can bloody name all the dinosaurs, all the big long names and that, ah I can't even pronounce them. He can pronounce them perfectly, so we know he is intelligent but you know to be told that, that's a big surprise when someone else sees that. I'm just proud of him cause I'm his mum, so I'm just proud of him so to be told that by someone else as well, it meant a lot to us I think. Cos obviously teachers and that don't pick up on that, they sometimes go with the negatives.</p> <p>Emma: Even though I want to take all this away from him, actually I don't because if I did that wouldn't be my James. That wouldn't be the boy that he is now. So...I'd want to take the pain away from him and the struggle that's he's got, but I would keep everything the same.</p> <p>Vicky and Paul: He's super clever where the computer is concerned. He's designing his own games, designs web pages, helped build up his own computer. He's so clever. and he's like "I'm going to go and work for Google" and I'm like 'you're going to own Google'. He's not going to work for them, he's going to own them! I can actually see that happening, I can actually see him being some kind of Steve Jobs...He is going to be Charlie Jobs. That makes me feel really happy, you know that makes me feel...you know I'm very proud.</p>
<p><b>The Emotional and Psychological Journey</b></p>	<p>Alone</p>	<p>Jane: If you've got a diagnosis they say right, we'll take you on all these training courses and we'll do all these things, but if you've got a diagnosis of non neuro-typical but we don't know why, or you know something like that, not at the moment...you sort of drift and you're alone. There's no counselling if you've had...or no one to talk to, because you can't talk to your husband cos it's painful. I'd listen to him, and you know we were both in a bit of pain and your sort of left.</p> <p>Melissa: Everything is sort of for you to find out yourself and that's ok if you've got that drive and that ability to do so, but if you haven't then your very very isolated.</p>

	<p>Martha: I've always thought some of his behaviours were peculiar but my husband didn't...I always suspected there was something wrong with his eyes and [husbands name] was like he's fine, but I thought it wasn't, you know mother's intuition they do say that and obviously it was right.</p> <p>Emma: My husband was in denial for a lot of the time. 'Oh he will grow out of it, it's nothing to worry about, he's just a naughty boy.' Hmm and my dad was very much the same as well, it was like, almost like they didn't want a stigma...cos I just felt like people saw me as this fussy mother, you know, which at the time I never really thought about it cos I was so focused on James but to not have the support from my husband it was hard. It was hard at the start.</p> <p>Vicky and Paul: I felt like I had nobody to turn to and just blocks put in front of me constantly.</p>
Judged	<p>Jane: All the time your thinking, I did say to Dr A I hope you don't think this is some sort of Munchausen by proxy thing. I'm not afraid to say that [laughs]. I'm afraid that you think that I'm thinking that, because obviously Oliver had been in and out of hospital for lots of reasons, medical reasons, and of course when it's medical you can see it can't you? He's having an asthma attack he can't breathe, ok erm and when he was in anaphylactic shock you know you can see that he's unresponsive, erm eczema we can see that he's covered in eczema, his eyes, you can see that he can't walk in a straight line, physio agreed etc. But something like this, it's not tangible is it?"</p> <p>Melissa: The information they got from that assessment um was just spot on you know, it was and it sort of highlighted everything that I had been saying, you know I thought well that's good it's not just me saying it you can see it.</p> <p>Martha: I was kind of relieved when I'd first seen Fiona on the first one, cos to be fair you think you doubt stuff cos you think it's all in your mind.</p> <p>Emma: You always get the sense that when your talking to people, you know because he hasn't had a diagnosis I kind of get the feeling that other people think...erm it's just in her head because they've said there's nothing you know...clearly wrong there...She's just making it up, or...It used to be really really hard to deal with. Now as time's progressing I kind of think well stuff what anyone else thinks. I'm wasting my energy now that could be used better you know, on something else. Because at the end of the day its doesn't really matter what they think.</p> <p>Vicky and Paul: I then began to think that it was just all in my head. <u>How was it thinking that?</u> Upsetting...because I don't think...I don't think it is all in my head...it's not. <i>It's not cos other people have seen it.</i></p>
Impact on self	<p>Jane: Well if you've got emotion in...not that it's not important of course, you need emotion in it cos it is very emotional, your son, your children are your life, they are my absolute world. But! if you've got too much of that bubbling up, then you're not thinking clearly, and it might come across like an emotional rant 'and look, what about me? what about me?' it might seem that it's all about you, 'what about me, and I'm not coping, and he's doing this and I'm not coping.'</p>

Melissa: It's, yeah, it's just sort of difficult at times you know? I have to sort of, I have to adapt, and sometimes it's difficult cos I have to adapt the way I sort of parent Erin...Gemma who's the older one [sister], says 'you treat Erin differently' or 'you expect um less from Erin' and that causes problems.

Martha: I didn't have any barriers. I think the only one with me was my memory, cos some of the questions Fiona was asking me, I was like God I can't think.

Emma: It's horrendous to think that he might be lonely, because when I drop him off at school...well I can't do anything then. I'm not there. I'm not in control of him. (sigh). Your heart just kind of sinks every time you drop him off at school. Some days it's too much to bare.

Vicky and *Paul*: They [older siblings] sometimes struggle. They get really narky with him and...you know...I...I'm the one whose saying 'try and understand, try and understand why he's being like this, he doesn't understand...' It's tiring. It's really tiring. There are times when I'm at home and I'm just like I can't...I can't cope...because it does cause friction [tearful]. I've got four kids not just...not just one, but Charlie takes up the majority of my time, he does, and erm...not even, not just sitting and talking to him but emotionally, my emotions are constantly worrying about Charlie and sometimes I feel that I kind of neglect the others.

Sarah: I worried, I didn't want to appear as if I talked about what the different things were as if to preempt what an outcome would be. So if anything I was very apprehensive about it all, because I thought oh God...I didn't want a label more than anything because I think him having the Dyslexia label had made him stop and think sometimes about what he is able to do and he uses it as an excuse not to do stuff.

Unrelenting  
Battle

Jane: [Says to the teachers] well we'll need to get support, [teachers respond] 'well we can't, we can't there's not money for support!', and you know then you suddenly go on the same old battle.

Melissa: You just feel you're continually fighting for services, fighting for support, fighting for a better life for her hmm sort of with the education board that's been a huge battle and you know most of my days off are sort of with, like erm phoning people or erm appointments or something and um sort of a lot of our time at home is sort of dominated by what Erin will or wont do.

Martha: She [the teacher] didn't seem to understand, cos I said he could have it. I she said we've thought to have him assessed but he could have it but she was still...every time I went in for a meeting she was still bringing the same things up. He keeps doing this, he keeps doing that, even though I explained to them, please be patient until we've had the assessment. So I think that's what made me go for the assessment to try and get other people to understand that if he did have it, because they just didn't seem to understand the way he was acting.

Emma: Exhausting. I'm exhausted. Especially with having three other children as well, who all need attention too. It is, it's exhausting...I just...If they did another assessment on him and you know still that came back that actually you know he's still borderline, you know that's ok. But it's the fact that you know I can see it, but they've just got a half an hour snap shot out of his life and based it on that.

		<p>Vicky and Paul: <i>Were back to square one, five years on.</i> Upsetting...and annoying. I'm...I go through the stages of...I get upset and then I get angry, cause I'm like 'For God Sake, why is he just being...nobody wants to help him. So then I get angry and defensive and...worry about his future.</p>
<b>Understanding the Outcome</b>	Lack of Closure	<p>Jane: If it's a yes it's more final sorry. If it's a yes, you've got a life time of this thing, if it's a no then you've got some uncertainty and that uncertainty might be good...might it?</p> <p>Melissa: So I think if you didn't have those support networks you could be really isolated. I think that's a huge thing, I think like some post diagnostic after the assessment, maybe in...I don't know...in three or four weeks' time or something to come back and to say right these are the numbers, these are the groups locally or something, this is what you could be entitled to. Um, just sort of that really. Um, would have been really really helpful. I think just to have it and then your left (laughs). And then sometimes I think well can I ring back if I'm having problems or do I not?</p> <p>Emma: He's struggling again in the classroom. When they went out to do his classroom assessment at the start of the year [sigh] they went on a day where it was his favorite subject. It was about insects. So of course he was absolutely enthralled. So as far as the assessment went, you know...there was nothing to show cos he was complying.</p> <p>Vicky and Paul: Well one person said he is on the autistic spectrum, but then the other person said well we're not sure he is on the autistic spectrum, however, we do think that he does need some help with his social skills. Even if you know we were just given some help you know on that, you know it just feels like I've just had a locked door...and now I'm having to find this key, that is on a key chain with about a million keys on it...you know it's just been shut the door, lock it and that's it.</p>
	Relief	<p>Jane: It wasn't easy to hear 'no', but it was easier that hearing 'yes'.</p> <p>Melissa: I think it has made me a bit more accepting of her behaviour, I think it's made me sort of deal with things differently. Um and try and sort of see things from her aspect and um sort of try and do things more at her pace rather than trying to push her into doing things that maybe she wasn't comfortable with and that's why she would behaviour the way that she did.</p> <p>Martha: It's helped lot you know, understanding why he is the way he is in that way cos we didn't know. We thought maybe it was something we'd done, you know is it the parenting, have we treated him like a baby? To me now, he's a normal kid.</p> <p>Emma: Initially I thought well maybe it is the right decision cause initially he did improve with his reading and his writing and his communication. I put that down to the school though.</p> <p>Sarah: It was a big relief! Because it's not just about school, it's about relationships and the rest of his life.</p>



## The Future

Jane: This is another thing that you hear as well, you have to wait and see if he tips over one way or another, he's going to tip over one edge or another...and it seems to be the case that you have to get to a crisis before you get to a result, do you see what I mean? That scares me for the future. So were obviously going to have to hit a crisis, or not, hopefully not...hmm before anything else d'know what I mean?

Melissa: You think 'oh gosh', you know, you think well what's the future going to hold and erm...I don't know, but I just tried to get her to do normal things.

Martha: It [the assessment] made us understand George a bit more I think and it's helped us a lot and helped us know where he needs help...it has helped us understand where we can help to bring him up, so I'm hoping that he wont need any help going forward with that, as long as the school are aware of it.

Emma: My thoughts are that if he was given a diagnosis, well at least there's that piece of paper to say James needs help, you know? So for me it would be a relief. Because whatever else happens it's there in black and white he needs help and there's people that can give it to me.

Vicky: He's now 13. He's going to be leaving school at some point and I just feel he is going to get to an age where they are going to say 'oh he is too old for us to give him some help now' and I've been trying for years to get him some help.

Paul: What's your biggest worry about the future? That he is gonna be taken advantage of by other people...and you never know what he said earlier on in life, that he shouldn't be in this world, it could resurface again couldn't it as he gets older, you know pressures of life?

Sarah: I suppose in some ways because school then have gone back to trying to resolve the bullying it's helped, because if it had of been the spectrum, then they would have just put it down to how Henry interprets things.

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All names have been replaced by pseudonyms; [text] context added by author; ... (speech hesitation); Underlined text denotes questions asked by the interviewer; Italicised text denotes Paul's speech during the joint responses in their interview.

## Appendix O

### Word Count Statement

#### Main Substance of Thesis

Thesis Title: 14

Thesis Abstract: 299

#### Chapter 1: Literature Review

Title Page: 64

Abstract: 250 (keywords: 7)

Main text (without tables, figures and references): 6623

Total: 6944

#### Chapter 2: Empirical Paper

Title Page: 104

Abstract: 116 (keywords: 8)

Main text (without tables and references): 6696

Total: 6924

#### Chapter 3: Contribution to Theory and Clinical Practice

Title Page: 15

Main text (without references): 4963

Total: 4978

**Main Substance of Thesis Total: 19,159**

#### **General Thesis Appendices (tables, figures, references and appendices)**

Chapter 1: Literature Review (References, figures and tables): 5170

Chapter 2: Empirical Paper (References and tables): 1058

Chapter 3: Contribution to Theory and Clinical Practice (references): 926

Appendix (excluding ethics proposal, correspondence and supporting material): 9940

**General Appendices Total: 16,168**

## Welcome to the Integrated Research Application System

## IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

**Please enter a short title for this project** (maximum 70 characters)  
Experiences of the ASD Assessment when a diagnosis is not received

**1. Is your project research?**

Yes  No

**2. Select one category from the list below:**

- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- Study involving qualitative methods only
- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank
- Research database

**If your work does not fit any of these categories, select the option below:**

Other study

**2a. Please answer the following question(s):**

- a) Does the study involve the use of any ionising radiation?  Yes  No
- b) Will you be taking new human tissue samples (or other human biological samples)?  Yes  No
- c) Will you be using existing human tissue samples (or other human biological samples)?  Yes  No

**3. In which countries of the UK will the research sites be located?** *(Tick all that apply)*

- England
- Scotland

- Wales  
 Northern Ireland

**3a. In which country of the UK will the lead NHS R&D office be located:**

- England  
 Scotland  
 Wales  
 Northern Ireland  
 This study does not involve the NHS

**4. Which applications do you require?**

*IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.*

- IRAS Form  
 NHS/HSC Research and Development offices  
 Social Care Research Ethics Committee  
 Research Ethics Committee  
 Confidentiality Advisory Group (CAG)  
 National Offender Management Service (NOMS) (Prisons & Probation)

*For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local collaborators.*

*For participating NHS organisations in England different arrangements apply for the provision of site specific information. Refer to IRAS Help for more information.*

**5. Will any research sites in this study be NHS organisations?**

- Yes  No

**6. Do you plan to include any participants who are children?**

- Yes  No

**7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?**

- Yes  No

*Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.*

**8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?**

- Yes  No

**9. Is the study or any part of it being undertaken as an educational project?**

Yes     No

Please describe briefly the involvement of the student(s):  
Chief Investigator

**9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?**

Yes     No

**10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?**

Yes     No

**11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?**

Yes     No

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**Integrated Research Application System**  
**Application Form for Research involving qualitative methods only**


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**Application to NHS/HSC Research Ethics Committee**

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

**Short title and version number:** (maximum 70 characters - this will be inserted as header on all forms)  
Experiences of the ASD Assessment when a diagnosis is not received

*Please complete these details after you have booked the REC application for review.*

**REC Name:**  
Wales REC 5

**REC Reference Number:**  
16/WA/0164

**Submission date:**  
12/05/2016

**PART A: Core study information**
**1. ADMINISTRATIVE DETAILS**
**A1. Full title of the research:**

Parents experiences of the Autistic Spectrum Disorder assessment process when the child did not receive a diagnosis.

**A2-1. Educational projects**

Name and contact details of student(s):

**Student 1**

	Title	Forename/Initials	Surname
	Miss	Lesley-Anne	Bendik
Address	North Wales Clinical Psychology Programme		
	School of Psychology		
	Bangor University, Bangor, Gwynedd		
Post Code	LL572DG		
E-mail	psp511@bangor.ac.uk		
Telephone	01248382205		
Fax			

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:  
Doctorate in Clinical Psychology (D.Clin.Psy)

Name of educational establishment:  
Bangor University

Name and contact details of academic supervisor(s):

**Academic supervisor 1**

	Title	Forename/Initials	Surname
	Dr	Freya	Spicer-White
Address	Wrexham CAMHS PO Box 2073 Wrexham Maelor Hospital		
Post Code	LL13-7ZA		
E-mail	Freya.Spicer@wales.nhs.uk		
Telephone	01978725242		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):

*Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.*

**Student(s)**

**Academic supervisor(s)**

**Student 1** Miss Lesley-Anne Bendik

Dr Freya Spicer-White

*A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.*

**A2-2. Who will act as Chief Investigator for this study?**

- Student
- Academic supervisor
- Other

**A3-1. Chief Investigator:**

	Title	Forename/Initials	Surname
	Miss	Lesley-Anne	Bendik
Post	Trainee Clinical Psychologist		
Qualifications	BSc Psychology MSc Applied Behaviour Analysis PGCert Psychological Trauma		
Employer	Betsi Cadwaladr University Health Board		
Work Address	North Wales Clinical Psychology Programme School of Psychology Bangor University, Bangor, Gwynedd		

Post Code	LL57 2DG
Work E-mail	psp511@bangor.ac.uk
* Personal E-mail	Lesley_anne1987@hotmail.com
Work Telephone	01248382205
* Personal Telephone/Mobile	
Fax	

*\* This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.  
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.*

**A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?**  
*This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.*

	Title Forename/Initials Surname
	Mr Hefin Francis
Address	School of Psychology Bangor University, Bangor, Gwynedd
Post Code	LL57 2AS
E-mail	h.francis@bangor.ac.uk
Telephone	01248388339
Fax	

**A5-1. Research reference numbers. Please give any relevant references for your study:**

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number: Bangor university: 1568

Protocol Version: 1

Protocol Date: 04/05/2016

Funder's reference number: N/A

Project website: N/A

**Additional reference number(s):**

Ref.Number	Description	Reference Number

*Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.*

**A5-2. Is this application linked to a previous study or another current application?**

Yes  No

*Please give brief details and reference numbers.*

**2. OVERVIEW OF THE RESEARCH**



*To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.*

**A6-1. Summary of the study.** *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.*

Autistic Spectrum Disorder (ASD) is a life long neurological developmental disorder. The process of obtaining this diagnosis for a child can be a difficult and emotional time for parents (Reed & Osborne, 2012). The majority of the previous research in this area has looked at parent's experiences of the ASD assessment process, when the outcome has confirmed that their child or young person does meet the criteria for this diagnosis. Such research has reflected the relief that parent's experience upon receiving a correct diagnosis, as this is often considered to be the key to achieving a level of acceptance and understanding of their child's emotional, behavioural and communication difficulties and most importantly access the appropriate support (Midence & O'Neill, 1999). However, there is very limited research on the experience of parents who go through the same assessment process, which can be lengthy and frustrating (Howlin & Moore, 1997), but for who their child's difficulties do not meet the diagnostic criteria and thus do not receive a diagnosis.

The aim of the present study is to explore the experience of parents/guardians whose child is assessed for ASD in a Child and Adolescent Mental Health Service in North Wales but who do not receive a diagnosis. To gain a true understanding of the lived experience of this group of individuals, the research will adopt a qualitative approach, whereby the participants will be asked to share their experiences in an interview with the researcher.

It is hoped that the outcome of this research will help clinicians understand how best they can support families through the assessment process. It is also hoped that the research will inform services of how to improve their approach to providing good quality information and provide guidelines on how best to communicate a non-diagnosis to family members.

**A6-2. Summary of main issues.** *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

*Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.*

**Purpose and Design:**

The purpose of this research to explore the lived experience of parents whose child/young person has been through the Autistic Spectrum Disorder (ASD) diagnosis process but have not received a diagnosis. This area has received little acknowledgement within the literature and therefore the researcher hopes the findings will contribute to the current evidence base and inform clinical practice. The researcher has chosen a qualitative approach to allow for a more in-depth analysis of the perceptions and experiences felt by these individuals. The research is being completed as part of a Doctorate in Clinical Psychological qualification and therefore its design has been approved by the research team at Bangor University and the academic supervisor who is an experienced Clinical Psychologist working within a Neurodevelopmental team.

**Recruitment:**

Clinicians working within the ASD diagnostic team within the relevant Child and Adolescent Mental Health Service (CAMHS) will inform potential participants of the research and issue them with an information sheet as part of their post assessment non-diagnosis pack, which is routinely provided within the current service. Potential participants will be asked to read the information sheet in their own time. They will be informed by the clinician that they can opt-out to being contacted by the researcher. They will also be informed that if they don't chose to opt out of being contacted, the researcher will contact them by telephone within four weeks of their appointment. It will be highlighted that this does not mean they have to participate. This contact will simply be to ask whether they have any questions regarding the research, whether they need any further information and whether they would like to take part.

Alternatively, if potential participants have already attended for their feedback appointment but who meet the criteria (received a non-diagnosis within the past 12months), the clinician will send the information sheet and opt-out form in the post accompanied by a letter introducing the purpose of the information. As above, they will be encouraged to complete the opt-out form and return this in the envelope provided within 2 weeks of the date of the letter should they not wish to be contacted. If the opt-out form is not returned, the researcher will contact them by telephone within four

weeks of the information being sent.

**Consent:**

The researcher will provide detailed information regarding the study prior to obtaining the participants consent. All participants will have the opportunity to take their time to consider this information and to ask questions. Informed consent will be obtained by the researcher in writing prior to conducting the research interview.

**Risks, Burdens and Benefits:**

Betsi Cadwaladr University Health Boards (BCUHB) confidentiality procedures will apply at all times throughout the research. Confidentiality and its limitations will be explained in detail to all participants prior to starting the interview. The nature of this research involves interviewing parents about a potentially difficult and stressful process of assessment for a life long diagnosis for their child. Therefore, whilst no distress or harm is intended, the researcher recognises that this is potentially an emotive subject, and asking parents to share their experiences may cause distress. The researcher will discuss this with all participants prior to the interview and will remain sensitive throughout. The participants will be encouraged to say if they do not wish to answer a question and they will be made aware that they can have a break, or that the interview can be terminated at any point. The researcher will signpost participants, with their consent, to their GP or to appropriate services to access support should this be necessary. All participant's will be offered a token gesture of appreciation (ten pound gift voucher) for their time and sharing their expertise with the researcher. As all interviews will take place within the local CAMHS service they have previously attended, their travel expenses will be reimbursed.

**Confidentiality and Data Management:**

Throughout the research all participants will be assigned a participant number to protect their identity. The research team will keep a record of the participant's name and corresponding participant number so that if any participants wish to withdraw from the study their information can be located and removed.

The interviews will be recorded on a digital recorder which will be kept in a locked filing cabinet. Following the interview these will be transcribed anonymously onto an encrypted device. All information collected throughout the project will be stored and managed in accordance with Bangor Universities policies and procedures, BCUHBs information governance policy and the Data Protection Act (1998).

When the results of the study are written up, direct quotes from the interview may be included. However, the researcher will follow strict guidelines to ensure that the individuals personal information is not included and that no-one reading the report will be able to identify the individual from the quotes or information included. For example, the participants name will be changed and any identifiable information will be removed. On completion of the research, all data will be deleted in line with the policies and procedures at Bangor University.

**A6-3. Proportionate review of REC application** *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

Yes - proportionate review  No - review by full REC meeting

*Further comments (optional):*

*Note: This question only applies to the REC application.*

### 3. PURPOSE AND DESIGN OF THE RESEARCH

**A7. Select the appropriate methodology description for this research. Please tick all that apply:**

- Case series/ case note review
- Case control
- Cohort observation
- Controlled trial without randomisation
- Cross-sectional study
- Database analysis
- Epidemiology
- Feasibility/ pilot study

- Laboratory study
- Metanalysis
- Qualitative research
- Questionnaire, interview or observation study
- Randomised controlled trial
- Other (please specify)

**A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.**

The principal aim of this research is to analyse parent's perceptions and experiences of the autistic spectrum disorder (ASD) assessment process. This question is specifically being asked to parents whose child has been through the process but whose difficulties do not meet the criteria for diagnosis.

**A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.**

What were parents experiences prior to the assessment; what difficulties did their child have, when were they first noticed and what did they hope to gain from the assessment process?

Whether they understood the assessment process and whether they felt heard, included and understood throughout the process?

Whether they felt their responses helped or hindered the process and outcome in any way?

What were their experiences following the assessment and whether their child has undergone any further assessment?

**A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.**

Autistic Spectrum Disorder (ASD) is a complex and lifelong neurological developmental disorder, which is thought to affect approximately 700,000 individuals within the United Kingdom (Baird et al., 2006). The process of obtaining this diagnosis, can be extremely distressing for parents but is often required as future care and educational support available to their child is usually dependent upon diagnosis (Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2010). In their large cross-sectional study, Keenan et al., found that parents reported their experience of the ASD assessment process as long, unclear, difficult to understand and that future planning/interventions were limited and did not involve full parental inclusion. They further stated that diagnosing a child at a young age and consequently providing the necessary intervention at the earliest possible opportunity is a major protective factor for families.

From a survey of almost 1300 parents of children involved with Autistic societies in the UK, Howlin and Moore (1997) found that 49% reported they were 'not very' or 'not at all' satisfied with the assessment process. Factors contributing to their dissatisfaction included long delays between raising their concerns and first being seen by a professional and the number of professionals seen prior to the diagnosis being made. Another important factor related to the given outcome and feedback appointment, as parent's satisfaction reduced when a vague explanation or outcome was given. For example, whilst almost 70% had eventually received a formal diagnosis of ASD, 26.7% of the sample reported that the given diagnosis was described as their child having autistic 'traits', 'features' or 'characteristics'. This diagnosis/description was reported as being particularly confusing and unhelpful. Only 29 people of the overall sample indicated that they had received a negative-diagnosis. However, these responses were not analysed separately and therefore it was not possible to determine whether their experiences differed from those who did receive a diagnosis.

Similar research documenting the difficulties parents have in navigating the ASD assessment process was presented by Siklos and Kerns (2007). They found that over 50% of their sample were dissatisfied both with the diagnostic process and with the lack of advice and support in the months following the outcome of their assessment. They highlighted that parents typically saw an average of 4.5 professionals in an attempt to obtain the correct support and diagnosis, and that they had typically waited 3 years from the time they first sought advice to the time the assessment was completed.

Whilst the assessment and diagnosis process has indicated to be an extremely stressful time for parents, and that a huge proportion of parent's report feeling dissatisfied predominantly with the length of time the process takes and the implications this has in terms of lack of support, the research has shown that 'relief' is often felt when the correct

diagnosis is provided (Mulligan, MacCulloch, Good & Nicholas, 2012; Reed & Osborne, 2012). A clear diagnosis and is considered to be the key to achieving a level of acceptance and understanding of their emotional, behavioural and communication difficulties and of course access the to appropriate support (Midence & O'Neill, 1999).

It appears that the emotional impact of this process on parents whose child is diagnosed with ASD is well documented. However, what remains unclear is the impact on parents who endure the same lengthy and frustrating process in the hope of achieving an explanation and support for their child's difficulties, but for who the outcome remains inconclusive as their difficulties are not deemed to meet the diagnostic threshold. This area is largely neglected within the wider literature and particularly within North Wales.

Therefore, the purpose of the current study is to explore the experiences of the parents in North Wales whose child presents with a number of social, communication and/or behavioural difficulties, and have been through the ASD diagnosis assessment process, but who did not receive a diagnosis. It is anticipated that parents may experience a range of emotions, which could include relief but also frustration, anger, disappointment, confusion, loss or hopelessness. The impact of such, could potentially interfere with the parent's ability to continue to manage their child's difficulties, their own health, and could also potentially have negative implications financially, if they feel they were dissatisfied with the process and wish to seek additional support or advice privately. This later point, is particularly relevant in North Wales at present, as there are currently no clear guidelines regarding a second opinion policy if parents are dissatisfied with the process or outcome of the ASD assessment.

Overall, it is important to understand the lived experiences of this group of individuals and in line with the National Service Framework and learn from service users' perspectives, in order to improve service delivery and professional practice. In particular, it is intended that this research will inform professionals on how to improve the ASD assessment and diagnostic process and how best to communicate a non-diagnosis to the family following the assessment.

**A13. Please summarise your design and methodology.** *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Parent/guardians whose child has been assessed for ASD, and who have not received a diagnosis, will be informed of the research by their CAMHS clinician during their routine feedback appointment and given information to read at home. Alternatively, the clinician will be send parents/guardian information regarding the research in the post if their feedback appointment had already taken place within the past 12 months.

They will be encouraged to complete the opt-out form either during the appointment (or return it within 2weeks if the information is sent by post) if they do not wish to be contacted regarding the research. If the individual is happy to be contacted, the researcher will do so by telephone within four weeks of them receiving the information sheet during their feedback appointment or in the post. This will give the individual ample time to read and process the information.

If the opt-out form has not been received within this time, the principal researcher will make contact with them by telephone to ask whether they have any questions regarding the research, whether they would like any further information and if they would like to take part. A telephone protocol will be adhered to.

If they agree to participate the researcher will arrange a convenient time to meet with them for one meeting at their local CAMH service.

During this meeting, the researcher will obtain written informed consent, and complete the research interview. Firstly, this will involve asking the participant demographic questions relating to their relationship to the child, the child's age at assessment, the child's gender, the length of referral time and the length of time since the assessment and feedback appointment took place. Secondly, they will be asked to share their experience of the ASD assessment process, prompted by a number of questions. The interview will last approximately 45-90 minutes in total.

Once the research interviews have been completed, the researcher will analyse the interviews using the qualitative method of interpretative phenomenological analysis (IPA). The researcher will write a brief summary of the findings and this will be posted to the participant by their local CAMH service.

**A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?**

- Design of the research
- Management of the research
- Undertaking the research

- Analysis of results
- Dissemination of findings
- None of the above

*Give details of involvement, or if none please justify the absence of involvement.*

The participant information sheet, the opt-out form, the consent form and the interview questions have been reviewed by a representative of service user panel, associated with the Doctorate in Clinical Psychology Programme at Bangor University.

**4. RISKS AND ETHICAL ISSUES**

**RESEARCH PARTICIPANTS**

**A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).**

Inclusion Criteria:

Parents and/or carers of children (5-19 years) who have been referred for an ASD assessment, and despite presenting with behavioural, communication and/or emotional difficulties do not meet the criteria for diagnosis. They will only be eligible for inclusion in the research once they have attended a feedback appointment and thus it has been confirmed that they will not receive a diagnosis based on the current assessment.

Parents and carers must be over 18 years of age.

The assessment must have taken place within the past 12 months.

The parents and/or carers will be selected from families who underwent the assess process within a Child and Adolescent Mental Health Service (CAMHS) within BCUHB. However, the principal base for recruitment will be from the Neurodevelopment Team (Wrexham and Flintshire CAMHS).

**A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).**

Exclusion Criteria:

Parents/Carers who do have the capacity to provide informed consent.

Parents/Carers whose child is already receiving professional support from another service in relation to the difficulties they have presented with. For example; Learning Disability Services.

Parents/Carers whose child receives another diagnosis, other than ASD, from the ASD assessment process. For example; ADHD.

**RESEARCH PROCEDURES, RISKS AND BENEFITS**

**A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.**

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
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Approached regarding the research during their routine feedback appointment, or sent information regarding the research in the post.	1	1	10minutes	<p>The individuals regular CAMHS clinician will approach the individual about the research during their routine feedback appointment and they will be given an information sheet to read at home. They will be encouraged to complete the opt-out form if they do not wish to be contacted regarding the research. If the individual is happy to be contacted by the researcher, the research will do so by telephone within four weeks of them receiving the information sheet during their feedback appointment. This will give the individual ample time to read and process the information.</p> <p>If the individual has already attended the appointment (in the past 12months) the individual will be sent the information sheet and opt-out form in the post by their local CAMHS clinician. They will be encouraged to return the opt-out form in the envelop provided within 2weeks of the date of the letter. If the opt-out form has not been received within this time, the researcher will make contact with them by telephone.</p>
The researcher will contact the individual by telephone.	1	0	10minutes	<p>The principal researcher (Miss Lesley-Anne Bendik) will contact the individual by telephone to ask whether they have any questions regarding the research, whether they would like any further information and if they would like to take part. A telephone protocol will be adhered to to ensure the individual is not put under any pressure to participate. If they agree to participate the researcher will arrange a convenient time to meet with them at their local CAMH service to complete the consent form and research interview.</p>
Informed consent will be obtained.	1	1	10minutes	<p>The principal researcher will discuss the research with the participant and check whether they have any questions. Written informed consent will be taken prior to beginning the interview.</p>
Demographic Questions.	1	1	15minutes	<p>The principal researcher will ask the participant questions relating to their relationship to the child, the child's age at assessment, the child's gender, the length of referral time and the length of time since the assessment and feedback appointment took place.</p>
Research Interview.	1	0	45-90minutes	<p>The researcher will ask the participant to give a detailed description of their experiences of the ASD assessment process.</p>
Feedback will be disseminated to all participants.	1	0	10minutes	<p>Once the research has been completed, the researcher will write a brief summary of the findings and this will be posted to the participant by their local CAMH service.</p>

**A21. How long do you expect each participant to be in the study in total?**

The time from when the participant will be first given the information sheet regarding the research to the time they receive a summary of the findings is anticipated to be approximately 18 months. However, the participants will only be actively involved in the research for approximately 3 hours.

**A22. What are the potential risks and burdens for research participants and how will you minimise them?**

*For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.*

The interview questions will invite the participants to share their personal experiences of their child going through the ASD assessment process. This could potentially elicit difficult emotions for the participant as they may find sharing their thoughts and experiences upsetting or distressing.

The researcher will make participants aware of this potential risk in the information sheet they will receive prior to consenting to participate in the study. This will also be discussed again during the consent process prior to the beginning of the interview.

The researcher will be sensitive to the needs of the participants and allow them to take regular breaks during the interview, skip questions they do not wish to answer, or terminate the interview. Should this situation arise the researcher will discuss this with the participant and allow additional time to work through their difficult emotions and agree on a decision together on how best to manage their emotional distress. The researcher will ensure she has

appropriate contact details for participants to access further support if appropriate, and with their consent will encourage them to access their GP. The participant will also be informed of their right to withdraw from the research at any time without reason or consequence.

It is anticipated that the participants may have certain expectations from the research team with regards to accessing psychological support. All participants will be informed that although the researcher is a trainee clinical psychologist and has the skills to manage emotional responses and distress during the interview, the aim of the interview is not to provide therapeutic input. However, as mentioned above if ongoing support is considered necessary the researcher will sign post the individual to an appropriate service, with their consent.

The participants will also be informed through the information sheet that not all the information they provide during the interview will be included in the final report, as this needs to be representative of all the individuals involved. They will be informed that regardless of whether their information is included in the final report or not, all the information they provide is extremely valuable.

**A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?**

Yes  No

*If Yes, please give details of procedures in place to deal with these issues:*

The interview questions will invite the participants to share their personal experiences of their child going through the ASD assessment process. This is a potentially emotive subject and at times participants may find sharing these experiences upsetting or distressing. The researcher will be sensitive to the needs of the participants and allow them to take regular breaks during the interview, skip questions they do not wish to answer, or terminate the interview. The participant will be informed of this prior to the interview and their right to withdraw from the research at any time without reason or consequence will be highlighted.

**A24. What is the potential for benefit to research participants?**

The researcher would like to offer a token gesture of a £10 voucher to all participants for sharing their time, experiences and expertise to improve professional knowledge and help the service and profession improve patients and family members experience of the ASD assessment process in the future. The participants will also be asked to attend their local CAMH service to complete the interview and therefore their travel expenses will be reimbursed.

Participants may also find it helpful or enjoyable to share their experiences and contribute to scientific research, which will potentially improve the service and experiences of other families who go through the same process in the future. All participants will be sent a summary of the results at the end of the study.

**A26. What are the potential risks for the researchers themselves? (if any)**

The nature of conducting in-depth interviews with participants who may share emotive experiences might have an impact on the emotions of the researcher. The researcher is a Trainee Clinical Psychologist who has the skills to manage difficult emotional responses and can access regular supervision from a Clinical Psychologist to discuss and manage her emotions if necessary.

**RECRUITMENT AND INFORMED CONSENT**

*In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.*

**A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).**

Potential participants will be identified by the clinician who is in charge of assessing the child/young person and providing feedback regarding the outcome of diagnosis to the family. These clinicians will all be employed by BCUHB and will be embedded within the CAMHS team where the child is assessed. In all feedback appointments, the family are routinely provided with an information pack to take home regarding the outcome of their assessment. When a

diagnosis has not been given the clinician will introduce the research at the end of the feedback appointment and include the participant information sheet within their pack. The potential participant will be encouraged to read this in their own time if they think they might like to be involved with the research. They will also be given the opportunity to complete an opt-out form. Completion of this form will mean the researcher will not contact them to discuss the research further. The clinician will inform the potential participant that if they do not complete this form, the researcher will contact them via telephone within four weeks of the appointment to ask if they have any questions, require more information about the research and to see if they would like to take part. They will be clearly informed that this does not mean that they are consenting to be involved in the research. Likewise, they will be clearly informed that should they wish to complete the opt-out form, they do not have to give a reason, and the care they receive from the NHS will not be affected.

Alternatively, if potential participants have already attended for their feedback appointment but who meet the inclusion criteria (did not receive a diagnosis following their assessment, within the past 12months), the clinician will send the information sheet and opt-out form in the post accompanied by a letter introducing the purpose of the research. As above, they will be encouraged to complete the opt-out form and return this in the envelope provided within 2 weeks of the date of the letter should they not wish to be contacted. If the opt-out form is not returned, the researcher will contact them by telephone within four weeks of the information being sent.

In the event that potential participants do not complete the opt-out form, and thus are happy to be contacted by the researcher, the clinician will provide the researcher with the individuals name and contact telephone number. This information will be given to the researcher, who is also employed within BCUHB, at the relevant service location (e.g. Wrexham CAMHS) and the researcher will make all telephone calls to the individual's from within the service base. This means that no personal information is taken off-site at any time; all information will be kept in a locked filing cabinet, in a locked room within the CAMHS service.

Once the researcher has made contact with the individual (using the telephone protocol) they will either arrange an appropriate time to meet with the individual if they wish to be involved in the research, or if they do not wish to be involved their contact details will be destroyed immediately.

**A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?**

Yes  No

*Please give details below:*

The individuals regular clinician will identify potential participants and inform them of the research at their feedback appointment or by post if they have already attended their feedback appointment within the past 12months. The information sheet given by the clinician will clearly explain that should they not wish to be contacted by the researcher they can complete the opt-out form, without reason or consequence. It will also be clearly detailed that if they don't not complete the opt-out form, this does not mean they are consenting to participate in the research, just that the researcher will contact them once they have had chance to read the participant information sheet to ask whether they have questions and whether at that point they would like to participate. Prior to any involvement in the research, the researcher will obtain written informed consent from all participants.

**A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?**

Yes  No

**A29. How and by whom will potential participants first be approached?**

The participants will first be approached by their CAMHS (Child and Adolescent Mental Health Service) clinician during their feedback appointment. The clinician will provide the parent/guardian with the information sheet in the information pack that all families are routinely given by the service following their assessment if the outcome is that a diagnosis is not given. The clinician will inform the family that the information sheet is included. They will have the opportunity to complete an opt-out form at the time if they do not wish to hear any further information regarding the research. If they do not chose to opt-out, the clinician will provide the researcher with their name and telephone number, and the researcher will contact them within 4 weeks of receiving the information to ask if they have any questions and discuss their participation further. It will be made clear to each individual that it is their choice whether they participate in the research.

Alternatively, if potential participants have already attended for their feedback appointment but who meet the criteria



(did not receive a diagnosis following their ASD assessment, within the past 12 months), the clinician will send the information sheet and opt-out form in the post accompanied by a letter introducing the purpose of the information. As above, they will be encouraged to complete the opt-out form and return this in the envelope provided within 2 weeks of the date of the letter should they not wish to be contacted. If the opt-out form is not returned, the researcher will contact them by telephone within four weeks of the information being sent.

**A30-1. Will you obtain informed consent from or on behalf of research participants?**

Yes  No

*If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.*

*If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.*

A detailed information sheet will be provided to potential participants in writing. They will also be given an opt-out form which the potential participant can complete should they not wish to be contacted by the researcher. The researcher will contact the potential participant within four weeks of them receiving the information to enquire whether they have any questions, require further information and whether they wish to participate in the research.

Prior to the interview the researcher will discuss all aspects of the information sheet and consent form with the participant and obtain written consent from them.

*If you are not obtaining consent, please explain why not.*

*Please enclose a copy of the information sheet(s) and consent form(s).*

**A30-2. Will you record informed consent (or advice from consultees) in writing?**

Yes  No

**A31. How long will you allow potential participants to decide whether or not to take part?**

The researcher will allow four weeks for potential participants to read the information sheet before contacting them to ask whether they have any questions and whether they would like to take part in the research.

**A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)**

All written information about the research study (e.g. information sheet, opt-out form, consent form) will be provided in Welsh and English. However, the interview will only be conducted in English, as unfortunately the researcher is not a Welsh speaker.

As the research is qualitative in nature and therefore requires participants to provide detailed descriptions of their experiences, any individuals who have a significant communication or learning difficulties will not be able to participate in the research.

**A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?**

All written information about the research study (e.g. information sheet, opt-out form, consent form) will be provided in Welsh and English. However, the interview will only be conducted in English, as unfortunately the researcher is not a Welsh speaker.

**A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.**

- The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- The participant would continue to be included in the study.
- Not applicable – informed consent will not be sought from any participants in this research.
- Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

*Further details:*

*If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.*

## CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

### Storage and use of personal data during the study

**A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)**

- Access to medical records by those outside the direct healthcare team
- Access to social care records by those outside the direct social care team
- Electronic transfer by magnetic or optical media, email or computer networks
- Sharing of personal data with other organisations
- Export of personal data outside the EEA
- Use of personal addresses, postcodes, faxes, emails or telephone numbers
- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals
- Use of audio/visual recording devices
- Storage of personal data on any of the following:
- Manual files (includes paper or film)
  - NHS computers
  - Social Care Service computers
  - Home or other personal computers
  - University computers
  - Private company computers
  - Laptop computers

*Further details:*

Following the ASD assessment process, a clinician within the service will complete a feedback appointment with the family. At this appointment the family are provided with an information pack about what it means not to receive a diagnosis of ASD. For the purpose of this research, to recruit participants, clinicians will add the research information sheet and an opt-out form into the information pack that is routinely provided. The clinician will inform families of this and provide highlight that should they not wish to consider the research they can complete the out-out form

attached. This will mean they will not be conducted by the researcher. If they are happy to be contacted, and thus do not complete the opt-out form, the researcher will contact the family within four weeks of their feedback appointment to discuss the researcher in further detail. They will clearly be informed that it is entirely up to them whether they would like to be contacted and be involved in the research.

Alternatively, if potential participants have already attended for their feedback appointment but who meet the criteria (did not receive a diagnosis following their ASD assessment, within the past 12 months), the clinician will send the information sheet and opt-out form in the post accompanied by a letter introducing the purpose of the information. As above, they will be encouraged to complete the opt-out form and return this in the envelope provided within 2 weeks of the date of the letter should they not wish to be contacted. If the opt-out form is not returned, the researcher will contact them by telephone within four weeks of the information being sent.

If potential participants are happy to be contacted, the clinician will provide the researcher with their name and telephone number. The researcher will telephone the individual from the CAMHS location they attended for assessment, to avoid any personal information being taken off-site. Once they have been contacted their details will be destroyed. Any personal details and contact information will be stored in a locked filing cabinet in a locked room at the relevant CAMHS base.

When the results of the study are written up, direct quotes from the interview may be included. This will be clearly explained to the participant in the information sheet prior to the interview, and there will be a separate box to tick on the consent form if the participant agrees to this.

The researcher will record all interviews on a digital record. After the interview, this will be kept in a locked filing cabinet until it is transcribed onto an encrypted USB-stick and then deleted from the recorder; the information will be anonymised prior to being transcribed. The encrypted device can only be accessed by the research team.

**A38. How will you ensure the confidentiality of personal data?** *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

Once the researcher has contacted the potential participants to ask if they would like to participate in the research and if so to arrange the interview this information will be destroyed. All participants will be given a participant identification number to protect their identity throughout the research.

**A40. Who will have access to participants' personal data during the study?** *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

Unless the potential participant completes the opt-out form, the clinician will provide their name and contact telephone number to the researcher. The individual will be made aware of this. If at this point the individual decides they do not wish to participate, their information will be destroyed immediately. If they do wish to participate, an interview time will be arranged and once they have attended for interview their contact details will be destroyed. In the meantime, these details will be securely stored in a locked filing cabinet in a lockable room at the relevant CAMHS location. These details will never be removed from the CAMHS base and no-one outside the research team will have access to this information.

#### Storage and use of data after the end of the study

**A43. How long will personal data be stored or accessed after the study has ended?**

- Less than 3 months
- 3 – 6 months
- 6 – 12 months
- 12 months – 3 years
- Over 3 years

#### INCENTIVES AND PAYMENTS

**A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?**

Yes  No

*If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.*  
The research participants will receive a ten pound gift voucher for as a token gesture of appreciation for sharing their time, experiences and expertise that will contribute to future service planning, protocols and the research evidence base. This gesture will not be used to entice people into participating in the research.

As all interviews will be held at their local Child and Adolescent Mental Health Service (CAMHS) their travel expenses will be reimbursed. The typical travel claims form at the relevant service will be used.

**A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?**

Yes  No

**A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?**

Yes  No

#### NOTIFICATION OF OTHER PROFESSIONALS

**A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?**

Yes  No

*If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.*

#### PUBLICATION AND DISSEMINATION

**A50. Will the research be registered on a public database?**

Yes  No

*Please give details, or justify if not registering the research.*

*Registration of research studies is encouraged wherever possible.*

*You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.*

**A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:**

- Peer reviewed scientific journals
- Internal report
- Conference presentation
- Publication on website

- Other publication
- Submission to regulatory authorities
- Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- No plans to report or disseminate the results
- Other (please specify)

**A53. Will you inform participants of the results?**

- Yes     No

*Please give details of how you will inform participants or justify if not doing so.*

The results of the research will be summarised and sent to all participant's in a leaflet. This leaflet will be sent out via the service so the researcher does not have to gain access to the participants address. Participants will also be invited to contact the researcher to discuss the results in more detail if they wish.

**5. Scientific and Statistical Review****A54. How has the scientific quality of the research been assessed? Tick as appropriate:**

- Independent external review
- Review within a company
- Review within a multi-centre research group
- Review within the Chief Investigator's institution or host organisation
- Review within the research team
- Review by educational supervisor
- Other

*Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:*

The development of this research was discussed and refined within the research team, which consists of experienced clinicians and researchers. A written proposal of the research was also approved by the North Wales Clinical Psychology research team at Bangor University.

*For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.*

*For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.*

**A59. What is the sample size for the research? How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.**

Total UK sample size: 10

Total international sample size (including UK):

Total in European Economic Area:

*Further details:*

The study will recruit a maximum number of 10 participants.

The research will adopt a qualitative approach, and thus the research team will aim to recruit a sample size of between 5-8 participants, as this will enable a thorough analysis of the participants lived experiences.

**A60. How was the sample size decided upon? If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.**

Smith, Flowers and Larkin (2010) recommend that researchers should recruit 4-10 participants when conducting research for Doctoral level qualifications using Interpretative Phenomenological Analysis (IPA).

**A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.**

The research will be qualitative in nature and the information will be analysed using Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009). IPA involves presenting the participants with a number of open ended questions to gain an insight into how they made sense of a given experience. This method will also enable the researcher to explore the meaning the participant has attributed to the given experience. IPA involves the researcher identifying themes within the participant's responses and using their interpretation to expand the themes further. The theory of IPA recognises that although the researcher aims to understand the participants true lived experience, this is reliant on their own conceptions, which are required to interpret the personal account provided by the participant.

**6. MANAGEMENT OF THE RESEARCH**

**A63. Other key investigators/collaborators.** Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.

	Title Forename/Initials Surname
	Dr Freya Spicer-White
Post	Lead Clinical Psychologist (Neurodevelopmental Team)
Qualifications	BSc (Hons) Psychology D.Clin.Psych (Doctorate in Clinical Psychology)
Employer	Betsi Cadwaladr University Health Board
Work Address	Wrexham CAMHS PO Box 2073 Wrexham Maelor Hospital
Post Code	LL13-7ZA
Telephone	01978725242
Fax	
Mobile	
Work Email	Freya.Spicer@wales.nhs.uk

**A64. Details of research sponsor(s)**

**A64-1. Sponsor**

**Lead Sponsor**

Status:  NHS or HSC care organisation

Academic

Pharmaceutical industry

Medical device industry

Local Authority

Other social care provider (including voluntary sector or private organisation)

Other

Commercial status:

*If Other, please specify:*

**Contact person**

Name of organisation Bangor University, School of Psychology  
 Given name Hefin  
 Family name Francis  
 Address School of Psychology  
 Town/city Bangor, Gwynedd  
 Post code LL57 2AS  
 Country UNITED KINGDOM  
 Telephone 01248388339  
 Fax  
 E-mail H.Francis@bangor.ac.uk

**Is the sponsor based outside the UK?**

Yes  No

*Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.*

**A65. Has external funding for the research been secured?**

- Funding secured from one or more funders  
 External funding application to one or more funders in progress  
 No application for external funding will be made

What type of research project is this?

- Standalone project  
 Project that is part of a programme grant  
 Project that is part of a Centre grant  
 Project that is part of a fellowship/ personal award/ research training award  
 Other

Other – please state:

**A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?**

Yes  No

*Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.*

**A68-1. Give details of the lead NHS R&D contact for this research:**

Title Forename/Initials Surname  
Dr Rossela Roberts

Organisation Betsi Cadwaladr University Health Board  
Address Clinical Academic Office, Ysbyty Gwynedd  
Bangor

Post Code LL57 2PW  
Work Email rossela.roberts@wales.nhs.uk  
Telephone 01248384877  
Fax  
Mobile

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

**A69-1. How long do you expect the study to last in the UK?**

Planned start date: 01/07/2016

Planned end date: 29/09/2017

Total duration:

Years: 1 Months: 2 Days: 29

**A71-2. Where will the research take place? (Tick as appropriate)**

- England  
 Scotland  
 Wales  
 Northern Ireland  
 Other countries in European Economic Area

Total UK sites in study

**Does this trial involve countries outside the EU?**

Yes  No

**A72. Which organisations in the UK will host the research? Please indicate the type of organisation by ticking the box and give approximate numbers if known:**

- NHS organisations in England  
 NHS organisations in Wales 1  
 NHS organisations in Scotland  
 HSC organisations in Northern Ireland  
 GP practices in England  
 GP practices in Wales  
 GP practices in Scotland  
 GP practices in Northern Ireland  
 Joint health and social care agencies (eg community mental health teams)  
 Local authorities



- Phase 1 trial units
- Prison establishments
- Probation areas
- Independent (private or voluntary sector) organisations
- Educational establishments
- Independent research units
- Other (give details)

Total UK sites in study: 1

#### A76. Insurance/ indemnity to meet potential legal liabilities

*Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland*

##### A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

*Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.*

- NHS indemnity scheme will apply (NHS sponsors only)
- Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet any legal liability of the sponsor for harm to participants arising from the design and management of the research. For information please see the attached letter.

*Please enclose a copy of relevant documents.*

##### A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

*Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.*

- NHS indemnity scheme will apply (protocol authors with NHS contracts only)
- Other insurance or indemnity arrangements will apply (give details below)

Bangor University will meet any legal liability of the sponsor for harm to participants arising from the design and management of the research. For information please see the attached letter.

*Please enclose a copy of relevant documents.*

##### A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

*Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.*

- NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
- Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

*Please enclose a copy of relevant documents.*

**PART C: Overview of research sites**

**Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites.** For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

Research site		Investigator/ Collaborator/ Contact	
Institution name	Neurodevelopment Team (East)	Title	Dr
Department name	Child and Adolescent Mental Health Service	First name/ Initials	Freya
Street address	Maelor Hospital, Croesnewydd Road	Surname	Spicer-White
Town/city	Wrexham		
Post Code	LL13-7ZA		
Institution name	Neurodevelopment Team (East)	Title	Dr
Department name	Child and Adolescent Mental Health Service	First name/ Initials	Freya
Street address	Catherine Gladstone House, Hawarden Way	Surname	Spicer-White
Town/city	Mancot, Flintshire		
Post Code	CH5-2EP		
Institution name	Denbighshire Child and Adolescent Mental Health Service	Title	Dr
Department name	CAMHS Clinic,	First name/ Initials	Lesley
Street address	1st Floor, Royal Alexandra Hospital, Marine Drive	Surname	Goodson
Town/city	Rhyl		
Post Code	LL18-3AS		
Institution name	Conwy Child and Adolescent Mental Health Service	Title	Dr
Department name	Child Health Premises	First name/ Initials	Helen
Street address	Argyll Road	Surname	Fitzpatrick
Town/city	Llandudno, Conwy		
Post Code	LL30-1DF		
Institution name	Child and Adolescent Mental Health Service	Title	Dr
Department name	Anglesey & Gwynedd CAMHS	First name/ Initials	Louise
Street address	Talarfon, Holyhead Road	Surname	Howard
Town/city	Bangor, Gwynedd		
Post Code	LL57-2EE		

**PART D: Declarations****D1. Declaration by Chief Investigator**

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
  - ◊ Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
  - ◊ May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
  - ◊ May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
  - ◊ Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
  - ◊ May be sent by email to REC members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

**Contact point for publication** *(Not applicable for R&D Forms)*

*NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.*

Chief Investigator

- Sponsor
- Study co-ordinator
- Student
- Other – please give details
- None

**Access to application for training purposes** *(Not applicable for R&D Forms)*

*Optional – please tick as appropriate:*

I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Miss Lesley-Anne Bendik on 05/05/2016 11:07.

Job Title/Post: Trainee Clinical Psychologist

Organisation: BCUHB

Email: psp511@bangor.ac.uk

**D2. Declaration by the sponsor's representative**

*If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.*

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

*Please note: The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.*

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by Mr Hefin Francis on 05/05/2016 11:39.

Job Title/Post: School Manager for Psychology

Organisation: Bangor University

Email: h.francis@bangor.ac.uk

**D3. Declaration for student projects by academic supervisor(s)**

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

**Academic supervisor 1**

This section was signed electronically by Dr Freya Spicer-White on 12/05/2016 08:27.

Job Title/Post: Clinical Psychologist  
Organisation: Betsi Cadwaladr University Health Board  
Email: freya.spicer@wales.nhs.uk

