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The experience of anxiety in adolescents with Autism Spectrum Disorder

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The Experience of Anxiety in Adolescents with Autism Spectrum Disorder

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This thesis is submitted in partial fulfilment of the regulations for the Doctorate in Clinical Psychology.

Contents

The experience of anxiety in adolescents with Autism Spectrum Disorder

This thesis is comprised of three pieces of work focusing on anxiety in children and adolescents with Autism Spectrum Disorder (ASD). The first is an original piece of qualitative research, investigating the lived experience of anxiety in adolescents with ASD. Interpretative Phenomenological Analysis (IPA) revealed three main themes; "the impact of anxiety", "managing anxiety" and "navigating relationships". Participants reported core features of ASD both causing anxiety and protecting against it, highlighting the complex interplay between the two. This led to the development of the literature review, which explored the overlap between ASD and Obsessive Compulsive Disorder (OCD).

This review had three aims. Firstly, to outline key similarities and differences between ASD and OCD in youth. Secondly, evaluating the use of OCD-specific assessment for youth with ASD. Finally, OCD-specific treatment for youth with comorbid ASD and OCD and was reviewed. 15 studies were included in the review. The results suggested key differences between ASD and OCD, for example in the overall number and type of obsessions and compulsions reported. In addition key differences in the function of behaviour, with obsessions viewed as intrusive in OCD and repetitive behaviour viewed as pleasure-seeking in ASD, were identified. Both the empirical paper and the literature review highlighted parents were crucial in supporting the young person with anxiety. This was also

highlighted as a potential implication for clinical practice, in relation to post-diagnostic work and as an emphasis within treatment. The final discussion paper explored current guidance for clinicians on the facilitation of post-diagnostic support and proposed suggestions for development in this area. In addition suggestions were made for clinicians to conduct thorough and comprehensive assessments for anxiety, alongside ASD, to prevent comorbid anxiety disorders being misdiagnosed. To conclude my personal reflections on completing this research project are discussed.

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Acknowledgements

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SECTION 2: Empirical paper: A qualitative analysis of the lived experiences of adolescents with Autism Spectrum Disorder (ASD) and co-morbid anxiety difficulties.

Notes for Contributors

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A qualitative analysis of the lived experiences of adolescents with Autism Spectrum Disorder (ASD) and co-morbid anxiety difficulties

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Title

A qualitative analysis of the lived experiences of adolescents with Autism Spectrum Disorder (ASD) and co-morbid anxiety difficulties.

Abstract

Anxiety is a common difficulty for young people with Autism Spectrum Disorders (ASD). More specifically social anxiety and obsessive compulsive disorder (OCD) are frequently reported as being the most common comorbid anxiety disorders in young people with ASD. However, there is limited understanding of the experience of anxiety from the perspective of individuals themselves. The aim of this study is to explore this utilising a semi structured interview approach. Seven adolescents aged between 13-18 were interviewed. Of the seven participants four were female and three were male and all had an established diagnosis of ASD and significant difficulties with anxiety. Interviews were transcribed and analysed using Interpretative Phenomenological Analysis. Three main themes emerged; these were 'the impact of anxiety', 'managing anxiety' and 'navigating relationships'. Limitations of the current study, areas for future research and clinical implications are discussed.

Key words: Adolescents; Autism Spectrum Disorder (ASD); anxiety; qualitative.

Introduction

Prevalence for Autistic Spectrum Disorder (ASD) in children is estimated at 1 in 160 [1]. ASD as characterised by marked impairments in social interaction and communication with repetitive behaviour and restricted interests, is subcategorised into Autistic Disorder (AD), Asperger's Syndrome (AS), Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) and High Functioning Autism (HFA) [2].

Although not diagnostic, it is well established that youth with ASD have more anxiety traits than typically developing children [3]. For the purpose of this paper the term "youth" refers to children and adolescents. A significant proportion of youth with ASD meet criteria for comorbid anxiety disorders [4, 5] with rates ranging between 11%-84% [6]. Variability in these rates may be due to many anxiety measures available for use in youth with ASD, having not been psychometrically evaluated using ASD samples [7].

Social anxiety, specific phobias and Obsessive Compulsive Disorder (OCD) were the most reported type of anxiety by youth with ASD [8, 9]. Bellini [8] found 49% of their sample of 12-18 year olds with ASD reported social anxiety, which is understandable given the social difficulties inherent in those with ASD. Those with high functioning ASD are aware of their difference and "disconnect" from others with a desire for this to not be the case [10], which according to White, Oswald et al. [6], often leads to anxiety

and social isolation. White et al. [6] also reported that anxiety levels differ depending on ASD subtype, those with AS have more anxiety than those with PDD-NOS, who in turn demonstrate more anxiety than AD. However the authors noted their findings regarding anxiety prevalence must be interpreted with caution as other factors, such as cognitive functioning, may impact on anxiety comorbidity.

Anxiety also relates to other features associated with ASD, such as communication deficits [11], poor social functioning [12] and social skills deficits [13]. Bellini [13] compared social anxiety across 41 youth with AS, AD and PDD-NOS. They found scores on physiological arousal and social skills deficits together significantly predicted social anxiety scores.

Little research has focused on what people with ASD have to say about their anxiety. Gillot and Standen [14] suggested it is important to capture these experiences when developing effective interventions, especially given the high prevalence of anxiety in those with ASD. To the author's knowledge only one study has used a qualitative approach to explore anxiety in young adults with ASD [15]. They interviewed two focus groups of participants aged 18-35 years and their parents/carers/spouses/professionals on issues relating to anxiety. Using thematic analysis [16] they identified three broad themes. Firstly "sources of anxiety", which included the environment, interactions and concern for others, fearful anticipation of events and disappointment. Secondly "the experience of anxiety" described how anxiety manifested itself and its

impact e.g. with sudden onset and preventing participants engaging in certain activities. The final theme addressed coping and described both preventative and management strategies for anxiety e.g. the use of escape. The authors noted their use of group-based interviews, which may have alienated potential participants given their significant difficulties in social communication.

As so little is known about the lived experience of anxiety among youth with ASD, aims of the current research are to explore this, allowing participants to talk about anxiety in their own terms, thus capturing their unique understanding. Furthermore a more interpretative form of thematic analysis will be used, Interpretative Phenomenological Analysis (IPA), which allows for more in depth exploration of individual experience.

Method

Participants

Seven participants were recruited, four female and three male, aged between 13-18 years. All had received their ASD diagnosis through a multi-disciplinary Child and Adolescent Mental Health Service (CAMHS) assessment. Four had received specific support for anxiety from either school counselling or CAMHS. (See Empirical Paper Appendix 1: Table 1 for details of participant characteristics).

Procedure

Following approval from the North Wales Research Ethics Committee, local CAMHS teams were approached. Clinicians' contacted potential participants by letter with attached participant information sheets and opt-in forms, which they could send to the researcher. Upon receipt of opt-in forms, the lead researcher contacted individuals to provide information and discuss the study in more detail. If the individual wanted to participate, an interview was scheduled within their home or CAMHS clinic.

As is typical in IPA, the sample size was small (n=7) and generally homogenous. Inclusion criteria were an established diagnosis of ASD; significant difficulties with anxiety based on either prior therapeutic involvement or parent/clinician report, and aged 11-18 years. Participants were excluded if they had an intellectual disability (IQ below 70) or active psychosis/thought disorder.

A semi-structured interview format was selected due to the flexibility in allowing participants to explore their own experience, whilst allowing for the exploration of topics of interest as they arise throughout the interview [17].

Broad topic areas were highlighted through knowledge of working with young people experiencing anxiety-related difficulties. Specific interview

questions were devised through collaboration with the second author and grouped under four main areas; 1) participant's experience of the assessment process and receipt of an ASD diagnosis, 2) triggers for anxiety, physical symptoms and factors impacting on anxiety, 3) strategies used to cope and manage anxiety, 4) experience of mental health services for anxiety. For those that had not received support, questions were based on what they thought might help them. See Empirical Paper Appendix 2 for interview schedule.

Interviews were conducted by the lead researcher across a three month period. Each participant completed one recorded interview lasting between 45 and 70 minutes. Six interviews were conducted in the participants' homes and one in a local child outpatient clinic. Prior to each interview participants were reminded of the study's aims and their right to withdraw at any time. Consent forms were signed and the audio equipment tested by the researcher and the participant. Following completion of each interview the researcher ensured participants were not distressed and knew how to access support if required. None of the participants indicated this was required. A gift voucher was offered and accepted by all participants for their involvement. All participants requested written feedback of the results.

Data analysis

IPA was chosen due to its flexibility in exploring individual experiences, recognising the individual as the expert in this. IPA is grounded in phenomenological theory (how things appear to the individual) and hermeneutics (the theory of interpretation). It is based on the premise that individuals, whilst presenting a certain way often conceal true feelings [18]. It is proposed that all interpretations are influenced by prior knowledge held by the interviewer, therefore a key aspect of IPA is raising awareness of this "double hermeneutic" to help the interviewer suspend preconceptions [19]. Thus IPA has a reflective element and is considered a dynamic process between interviewer and individual.

Upon completion the lead researcher transcribed all interviews verbatim. Data was analysed according to the process described by Smith, Flowers et al. [19]. Transcripts were read in their entirety for the researcher to become familiar with the data. During this, exploratory comments were made in the margins to summarise key points. Transcripts were then re-read and the opposite margin used to capture emerging themes. See General Appendix 1 for an extract from an analysed interview at this stage.

Following this emerging themes were clustered together based on conceptual similarity across all transcripts. The clustered emerging themes were further grouped to form broader subthemes. In order to reduce the size of the data, whilst retaining the meaning and complexity of its content,

these subthemes were further combined to generate superordinate main themes that captured the overall concept of related subthemes. To organise the findings a master table was generated outlining main themes, associated subthemes and clusters of emerging themes (see General Appendix 2 for an extract of this table). Once the master table was created it was used as the basis for creating the narrative account of what participants said, combined with the interpretations of the researcher. In IPA creating the narrative account is part of the analytic process and refinement of themes and subthemes continues.

As the narrative account developed themes were reorganised and refined ensuring that the overall account was concise and representative, whilst still capturing the meaning and context of individual interviews/participants. The theme "sense of self" can be used to illustrate this process. Prior to developing the narrative account "sense of self" was used to capture how participants viewed themselves and how anxiety is linked to this e.g. being anxious about appearing different to others. However, by referring to individual transcripts, considering the structure of the account as a whole and discussion with the second author, it was felt the concepts in this theme were better represented when incorporated into a broader theme about how participants interacted and related to others. Thus it was felt that the theme "navigating relationships", in particular how certain relationships impact on anxiety, was a more appropriate descriptor in this case. Therefore "sense of self" was not present in the final account.

To enhance the reliability and validity of the IPA analysis, a process of triangulation [20] was undertaken with the second author. This involved transcripts being read separately and themes checked for relevance, with alterations made when required.

Results

Overview

Three core themes were identified, "The impact of anxiety", "Managing of anxiety" and "Navigating relationships." Each core theme is described below along with corresponding subthemes. Quotations are used to illustrate interpretations made. (See Empirical Paper Appendix 3: Table 2 for main themes with corresponding subthemes).

Theme 1: The Impact of Anxiety

Immediate effects of anxiety

All participants experienced anxiety on a daily basis and clearly described their physical symptoms of anxiety. These ranged from common symptoms of anxiety such as headaches and stomach-aches to more extreme symptoms e.g. dizziness and shaking limbs.

"Erm I have a belly ache sometimes I feel dizzy and feel like I'm going to be sick." (Sarah)

All participants felt their anxiety impacted on their daily functioning. This resulted in limited concentration, which hindered performance in school and at home. Daniel reported reduced ability to think clearly when anxious which impacted on his schoolwork.

"Whenever in school and I go and I have to talk about these things, do work around it, I can often, I would, my handwriting will start going bad cause I can't really, I can't think clearly." (Daniel)

Participants described an inability to think clearly at school that hindered their ability to communicate with others. For some, anxiety could build up so they felt unable to leave their home.

"I struggle to form…I'm usually quite eloquent, that is something my teachers note in my reports and stuff, and I just go to I go to rat s**t and just go ah ba bab ba." (Simon)

"Sometimes well I couldn't leave my house to go to sleepovers." (Harry)

Two participants worried their anxiety might lead to loss of control and acting out of character.

"I was worried like I'd do something. I wouldn't hit the dog, I'd never hit a dog ,(…) I was worried that I'd do something what I don't really want to do." (Emma)

"I am afraid of losing control, kind of myself, I'm afraid of starting like a fight." (Daniel)

Emma and Daniel talk about their anxiety as being out of their control, and as being powerful enough to result in behaviour which conflicts with their ideals and values. It is likely that this may result in feelings of unpredictability and uncertainty and a lack of control over their own behaviour. This feeling of being out of control is likely to be particularly confusing and difficult for those with ASD, who often display a preference for routine and ritualistic behaviour. Thus anxiety is a pervading part of participants' lives, one that participants do not feel in control of.

Causes of anxiety

Participants talked about what made them anxious, the most common cause for anxiety was anticipatory thoughts. These were divided into four subcategories; 1) socialisation, 2) irrational thoughts, 3) obsessional thoughts and 4) hypothetical thoughts which included meta-worry (worrying about worry itself).

1) Socialisation

Some thoughts about socialisation e.g. worries about what others will think of them, fear of being judged by peers etc. were not unreasonable given these participants were dealing with usual adolescent issues and had the additional complexity of having ASD. All participants were aware of their own ASD and understood it meant they struggled with aspects of social communication. Being unsure about what they sometimes got 'wrong' socially, led to anxiety.

"Erm I'm a bit scared of speaking in class (…) because if I say something slightly wrong sometimes people laugh and I don't like that." (Sarah)

Four participants were especially worried about being judged by their peers, or about unintentionally offending others during conversation.

"Yeah yeah I always think they'll think oh she's crazy, she's a nutter, what's wrong with her, things like that." (Jane)

"I'm much better, sometimes I'll say things that are inadvertently quite acerbic or nasty". (Simon)

Participants' worries about unintentionally offending others seem to come from past experiences of saying things that upset others, as well as being aware of how having ASD made them different from others e.g. tendencies

to speak literally without adapting to different contexts. As highlighted by Harry, participants may be aware they have said something wrong but find it difficult to rectify this immediately after doing so. This may further exacerbate their anxiety, as their experience of social interaction is one of failure and not being under their control.

"It does happen quite a lot where I'd just end up saying something offensively and they'll give you that kind of look and you'll go 'oh no' and you have that moment like 'I know what I've done but I'm not going to be able to stop it now'. So that's a bit hard to deal with." (Harry)

In social situations two participants felt they did not always understand the actions of others or what may happen, which often contributed towards anxiety.

"The problem is (…) I don't really understand like erm what their actions are or why they're talking like this, what they're going to, what are they going to do." (Daniel)

"I get anxious because I don't know what's going to happen". (Sarah)

For some participants, the unpredictability and uncertainty of such social situations was a root cause of anxiety. This paralleled participants' descriptions of dealing with unpredictability, which came from an anxiety-induced loss of self-control; however the difference here was that it is the

unpredictability and uncertainty of others, rather than themselves, which were regarded as a cause of anxiety.

2) Irrational thoughts

Participants described experiencing strong, fearful thoughts, for example about injections and cleanliness, which they knew, had little bearing on reality, yet were beyond their perceived control and contributed greatly to anxiety on a daily basis.

"I know that nothing's going to happen but you just feel, you feel like it is, and your set in it in your head that it is, even though you can say "I know nothing is going to happen", you know nothing is, it's set in your head that it is." (Harry)

"The thing is I know the injections will do me good, but I also, but I just have this irrational fear about it" (Daniel)

One interpretation is that being aware a thought is implausible does not prevent the rise of anxiety-related physical symptoms. Participants may therefore become overwhelmed in the moment by physical sensations that prevent them being able to control their thought process and this cause's them to react fearfully to thoughts they know are irrational.

3) Obsessional thoughts

Two participants reported experiencing obsessional-type thoughts. These were focussed on a specific worry, which they found difficult to distract themselves from. For Harry, this was thoughts of being contaminated by others.

"I just, I'd have to stay away from 'em [brother's friends], if they touch me I'll have, even if it's on my clothes, I'll have to go and like wipe it even though I know it wouldn't go, I'd have to wipe it. If they touch my arm or anything like on my shoulder or anything I'd have to get the sink and actually wipe at my shoulder, just coz like, I can't handle germs or being ill." (Harry)

This is an example of a particular type of cognition that may indicate that anxiety experienced within ASD can develop into a specific disorder diagnostic in itself such as OCD. Here the anxious thought is followed by a compulsive behaviour designed to reduce anxiety. Harry's quote suggests that his compulsions alleviate distress, a factor that could be used to identify OCD in ASD, as often repetitive behaviours are considered more syntonic and pleasurable in ASD.

4) Hypothetical thoughts

Two participants reported worrying about hypothetical situations. Emma reported ruminating daily about future situations, which may be considered unusual for a 13 year old girl, such as being arrested or not having a child. The frequency and intensity of her ruminations can be considered obsessive in nature, as it interfered with her functioning in school and at home due to the amount of time it consumed.

"Well I keep having like nervous dreams like when I'm older, like I'm going to smoke, I'm going to get arrested (…) I keep worrying about that." (Emma)

"I really am worried that when I'm older my life will be really messed up, I won't have a family, I won't have a kid." (Emma)

The above quotes highlight the difficulty Emma has in letting go of her worries about the future, which may reflect rigidity commonly, associated with ASD. Simon spoke about meta-worries. He worried extensively that his worrying would prevent him doing certain things in the future such as driving a car, and generally prevent him from achieving future goals.

"And on a more long-term basis sometimes I worry that my worry is going to get in the way of my life proper. That I'm never going to be able to drive

a car coz I might worry about it, I'm never going to be able to go abroad coz I might worry about it." (Simon)

Whilst the subject of Emma and Simon's worries differed, the two can be considered similar in that they are concerned with anxieties about the future, which they can do little about in the present.

Theme 2: Managing Anxiety

All participants attempted to control or manage their anxiety, using a variety of strategies. The most common were avoidant and distraction based strategies such as withdrawing from a situation and listening to music. Far less commonly reported were the use of taught techniques including mindfulness and graded exposure.

Avoidance/escape

Five participants reported using avoidance or escape as a way of coping with anxiety. This happened in one of two ways; either by attempting to avoid internal experiences or by avoiding external sources of anxiety such as social interaction.

"Something I thought of was I need to get to sleep [when I have anxious thoughts] because when I wake up in the morning I'm fine....so I go to bed." (Sarah)

"I basically try to avoid contact with other people and I try not to provoke attention." (Daniel)

"Some days I'll try and be like, oh try and act up, so I'll be like 'mum I don't wanna go in, I don't feel well', because I don't want to face that teacher". (Jane)

Participants described how these avoidant strategies alleviated anxiety in the short-term. However no participant demonstrated an awareness of the negative impact avoidance would perhaps have on being able to face and challenge similar situations in the future. Jane's anxiety derives from the thought that she does not want to face the teacher, as she may not meet the teacher's expectations. This leads to attempts to avoid the situation by lying to her mother. She may experience short-term relief but in the long-term her avoidance prevents disconfirmation of her worries and potentially undermines her confidence in facing the teacher next time. Thus anxiety is maintained.

Participants acknowledged they had difficulties and felt seeking support from others could help, but simultaneously acknowledged they would avoid going to others for help. One participant had concerns about being judged by those she would seek help from.

"I've tried to improve on how to learn to talk to people about my problems and things, but I still think that people will judge me, what I tell them (…) I try not to talk to people about it." (Jane)

When Jane avoids talking to people about her difficulties this is likely to maintain them by preventing her seeking support from others. She does acknowledge this and is trying to "learn to talk to people" which suggests this is something that has to be consciously developed or learnt rather than coming naturally or intuitively. This could reflect an underlying deficit in social interaction, which is one of the core aspects of ASD, and can play a significant role in making it difficult for young people with ASD to manage anxiety.

Distraction

Five participants used distraction techniques to cope with their anxiety. This ranged from talking with family members whilst in public, to reading or listening to music.

"Erm, it works when we go out to eat sometimes and I get anxious when I am going out to eat, so we just talk and that works and I can eat more because I am distracted." (Sarah)

"I would sometimes read a book, watch something to cheer me up. I try, I try, to find a way how I can forget my anxiety." (Daniel)

Participants described various distraction-based strategies and their effectiveness. Participants did not comment on how effective these were in the long-term, only how effective they were in the moment. Indeed, one advantage of distraction is the immediacy of its effect. As Sarah highlighted, distraction can allow individuals to continue engaging in their current activity, such as eating in public. It may also be that distractions are effective for participants because they provide practical ways to shift attention away from anxious thoughts, thoughts that may be more rigid in those with ASD.

It is important to consider the relationship and possible overlap between distraction and avoidance-based strategies. Whilst distraction can be effective in reducing anxiety in the short-term, it can also be an attempt to avoid particular anxious thoughts, as can be interpreted by Daniel above. Whilst he found reading or watching television an effective distraction technique, it appeared he was doing this to avoid the anxiety he was experiencing beforehand.

Taught techniques

One participant described mindfulness as being effective in reducing anxiety. He had been taught this technique through individual therapy at CAMHS and whilst he found it difficult to initially implement, regular practise made it something he wanted to continue using throughout his life.

"The other thing that I sometimes do is I'll make a point of getting a piece of chewing gum out and you know, well it's a CAMHS thing, do it very slowly, very deliberately, very mindfully (…) [it's] very useful, it's probably the most useful thing they've kind of left me with." (Simon)

"I started off at home doing it when I wasn't stressed, you know about anything like putting your socks on, brushing your teeth, and then when I was stressed I kind of practised and knew what to do, what to expect, and yeah I'd say it requires a lot of practice." (Simon)

As highlighted by Simon mindfulness can be very effective in managing anxiety and may not maintain difficulties in the way distraction and avoidance-based coping strategies can. In the initial stages mindfulness makes use of specific practice exercises that often include discrete steps to follow. This way of learning may appeal to those with ASD who often prefer such routine-based and predictable/structured approaches.

Hyper-vigilance of self and others

Another commonly reported strategy for coping with anxiety was being hyper-vigilant about one's behaviour and surroundings, and to monitor and adapt accordingly. While this could be useful in some circumstances, for Sarah, she seemed to closely monitor her own behaviour in an attempt to tightly control it.

"Just be careful how I'm saying things and how I would look when I am saying them, just in case they think I'm in the wrong, because if they think, I mean, like if I'm meaning something happy but I use the wrong tone of voice, they might think I'm angry." (Sarah)

Simon described varying the type of self-monitoring he did according to the quality of relationship he had with others.

"If you're with a complete stranger or someone who doesn't like you, you have to really watch your footing, checking that you're saying the right things. If I'm with someone who's on reasonably good terms with me, then I can, if I make an accident, I go "sorry, sorry tired." (Simon)

It is likely there is some overlap between this being a coping strategy and a result of feeling anxious. Being more vigilant of one's behaviour can prevent appearing different from others, however by excessively focusing on this, it can add pressure to perform, increase anxiety and make the internal experience of having a social interaction much more tense and difficult.

Management of routines: The double-edged sword of ASD

A common feature of ASD is a preference for routine/structure and predictability and difficulty managing change. Participants described

managing much of their life using a predictable routine, which also helped manage their anxiety. At the same time, this rigid adherence to routine meant that if it was disrupted, intense anxiety often arose.

Three participants described how aspects of their ASD (e.g. a preference for structure and routine) positively influenced their anxiety.

"Erm I would say the ASD helps me cope with anxiety better (…) erm my mind is quite structured and analytical, and quite, I like lists." (Simon)

"I need a routine to like help me in my lifetime." (Emma)

Four participants described the negative consequences that often arose from routines being disrupted and unexpected change often resulting in feelings of anxiety and distress.

"If I got told straight away, now we're going on a train or something, it'd just set me completely off. I'd have to be told a couple of days before or a week beforehand." (Harry)

Whilst having a routine/plan can be helpful in some instances, there are many things in life that cannot be planned for. Based on the experiences of the seven participants interviewed in this study a tentative conclusion can be drawn. This is that individuals with ASD who rely on this way of coping to manage all aspects of life quickly run into difficulties, as they are unable

to flexibly adapt when unexpected events occur, thus panic and anxiety ensues. The inherent difficulty to generalise qualitative findings to a population contributes to the tentative nature of this conclusion.

"Er because people come around unexpectedly it kind of ruins the order due to my ASD. Well because I have ASD, I have to like plan out the day and because people just disrupt it I start feeling panicky, I don't know what to do. I try to hide my, I try to stay away from people, from anybody else." (Daniel)

Theme 3: Navigating Relationships

Participants mainly talked about three areas of relationships with others and how they impacted on their anxiety: family, peers and professionals. These relationships contributed to anxiety at times whilst others provided support.

Home life

All participants described their family life, such as their role within the family and the difficulties arising from living within a family. Four participants described home being a place of refuge in times of anxiety, with some having safe places within the home, such as a bedroom to listen to music in or to be alone.

"Err, not sure I'll be just, what I do is just, think of other stuff and if I'm at home I'll go and sit in the bathroom, it's like my place that will calm me down from it." (Harry)

As well as a place of refuge, home life could also be difficult. Simon described how spending time with his family could be tiring and increased his feelings of anxiety by making him think he had upset or "disappointed" them. Jane reported that she taught herself to leave the family room when anxious, to stop her family from seeing her in that state.

"It makes it more tiring it means I spend less time with them. I would sometimes just prefer to be on my own in my room and only have my head to deal with, than to go downstairs and spend some good time with them. (…) But then come back and spend two hours worrying about you, have I said the wrong things to them, have I upset them, have I disappointed them." (Simon)

"I'd cry and have to walk off because I didn't want my brother and sister seeing me in that kind of a state…. so I just had to leave, but it took me a while to do that, for me to teach myself." (Jane)

"Mums been like a rock to me": Parental relationships

There was a clear difference between the roles mothers and fathers played in the lives of participants. Four participants described mothers as being

the primary source of support for their anxiety, feeling that their mother understood more about ASD and their difficulties and was more available. Participants described how their father seemed to understand less about ASD and anxiety, and were less likely to make the necessary adaptations to their behaviour. Fathers were also perceived as less available due to work commitments.

"Erm I had two years off school and my mum was pretty much, dad's out at work, he works quite long hours (…) whereas my mum for those two years (…) was pretty much the only person I saw." (Simon)

"But my dad will still continually say these things, these kind of things and then I will say to him "that's not funny", or "I don't understand it" or.... and my dad'll just go "what on earth?" (…) so I don't think he quite understands (…) why I don't get them." (Jane)

From the above quotes it is clear that availability may be a key factor in shaping a supportive relationship between a young person with ASD and anxiety and their parent. It must be noted that this conclusion is drawn from the experiences of the seven participants interviewed and as such the small sample size prevents generalisabilty and at this stage the conclusions drawn should be viewed as tentative. Availability and therefore exposure to the child's difficulties often leads to increased understanding of such difficulties and more opportunities to develop ways to effectively manage them. In addition the parent that has more understanding may be more

likely to adapt their own behaviour accordingly, something participants appreciated.

Professional supportive relationships

Four participants received support from either school or CAMHS. Central to a supportive, professional, therapeutic relationship was feeling understood without being judged. Simon described how talking to someone who was paid to listen prevented him feeling like he was burdening the therapist. Jane described how having someone in her school that understood and knew how to help her when she was anxious, was really helpful.

"I feel like I'm talking about myself at length and going on about myself, but it was nice to speak to someone who was paid to do that as their job, so you weren't burdening some random person." (Simon)

"There was a learning support and I had a time out card and I just had to show the teacher that and then, I erm, the teacher would allow me out, I'd walk down to the learning support centre where there's a teacher who knew all my needs and what helped relax me and calm me down." (Jane)

Trust and reliability was also reported to be an important characteristic of professionals. Simon highlighted the positive effect a reliable and attentive professional can have on the therapeutic relationship, placing importance on practical aspects such as punctuality.

"They were very good about sticking to their times and their routines, you, I know, I knew what day I was going, it was prearranged and they were dead helpful." (Simon)

Emma highlighted the negative impact the therapist not sticking to an arranged time can have on engagement, by creating a sense of mistrust and unreliability, and also lead Emma to question the motives of the therapist.

"I go there, the door's locked and I wait there until the end of break, but she's never there (…) and I would like, I'm visualising that she's stitching me up, like she wants me to go and waste my break time and wait for, but she's not there." (Emma)

Unexpected change and unpredictability can cause anxiety for participants. Therefore it is understandable that trustworthiness and reliability is a sought after characteristic. In addition having a sense that someone is not going to judge you and understands your feelings and experiences may make it easier for participants to discuss difficulties. This may particularly be the case if an individual feels family don't understand or are judgemental as highlighted in the quotes below.

"Just like with my family. I'm worried they'll judge me". (Jane)

"I think it was someone who you could occasionally talk to who kind of

understood what was going on in your head, who could explain it better to you than Internet or your mum or the book, you know. That kind of thing, I think that's why it helped me." (Jane)

Disclosing an ASD diagnosis to others

Participants had different attitudes towards their ASD diagnosis. Five participants concealed it from peers, which impacted upon their anxiety in a number of different ways. Emma chose not to tell people about having ASD as she thought others would make fun of her, and this contributed to her anxiety regarding future disclosure. Other reasons given for concealment were not being believed and past experiences of losing friends once they found out, which all contributed to anxiety about possible future rejection.

"When people told me, asked me if I've got autism, I just lied, I said no (…) because if they found that I did, or if I said yeah, then they will make fun of me". (Emma)

However, for four participants, receiving a diagnosis of ASD provided them with an explanation for their difficulties and therefore helped them accept themselves and thus reduced their anxiety somewhat.

"Now I know that I'm autistic and now I know that's why I'm not a people person (…) I think oh right well I'm doing quite well then, if I'm you know,

for a disabled person (…) So it's made me feel better about myself." (Simon)

However, for others, their own negative perception of their ASD further exacerbated their anxiety and as a result they tried to conceal their diagnosis from others, rather than accept it. These two things did not appear to be exclusive, as some participants were able to accept their diagnosis, but still worried that if peers found out there would be negative consequences, such as rejection.

Having an ASD diagnosis made social relations more complicated for some participants, as they felt different from others and had to make a decision about whether to share their diagnosis with others. However, on an intra-personal level the diagnosis sometimes reduced anxiety as it provided an explanation of differences.

Discussion

The aim of this study was to explore the experiences of anxiety in youth with ASD and it is the first study to explore this from the individual's perspective. Three overarching themes emerged; the impact of anxiety; how young people with ASD manage their anxiety and the way anxiety affects the development of relationships.

All participants described how anxiety permeates their whole lives affecting school, home, and relationships. Anxiety was reported to be

caused by many interlinking factors, such as a fear of being rejected and not understood by others, through a variety of anticipatory thoughts and feeling that the actions of others were difficult to understand and therefore unpredictable. In addition anxiety led to feeling that one's own behaviour became "out of character" and therefore unpredictable, which further exacerbated anxiety.

The most common coping strategy reported was using avoidance/escape. This appeared to be effective in the short-term; however the potential for this to maintain difficulties was not reported. The way avoidance maintains anxiety is well established in the general population [21], as it prevents individuals confirming or disconfirming their fears about situations, therefore avoiding them in the future. The current findings suggest such this may also apply to youth with ASD.

The way in which participants reported coping with their anxiety supports findings by Trembath et al. [15] who found young adults with ASD frequently use distraction to cope with anxiety. Within the current study some of the common features of ASD such as a preference for routine and structure were conceptualised as a "double-edged sword" for participants. For some planning for and structuring discrete upcoming events helped them manage anxiety e.g. writing lists. However those that applied this coping strategy more globally appeared to have exacerbated anxiety, as the nature of some events were unpredictable and not suited to this method of coping, e.g. being spontaneously asked to do something or go somewhere.

Whilst the findings of the current study map onto those of Trembath et al. [15] there are two additional areas of interest reported in the current study. These include the role of anticipatory thoughts and factors that lead to supportive relationships.

Anticipatory thoughts as a cause for anxiety

The most common cause of anxiety reported by participants was anticipatory thoughts subcategorised into four main types of thoughts including: socialisation, irrational, obsessional and hypothetical rumination. Of particular interest were thoughts about socialisation and the way in which youth with ASD were able to identify some thoughts as irrational.

In relation to socialisation, most participants reported a fear of being judged by others and an awareness of their social skills deficits, such as offending others. This was in part due to difficulty adapting their behaviour when interacting with others, therefore leading them to behave in a way that may offend others or make them stand out from their peers. In turn this made maintaining friendships difficult. Participants discussed how some of these thoughts were based in reality, which was likely to reinforce their anxiety for future situations. This supports literature that suggests social anxiety is high amongst youth with ASD especially in those with insight of such difference [10, 8]. It was found in the current study that an

awareness of the irrationality of some anxiety provoking thoughts did not prevent the onset of anxiety which fits with experiences in clinical practice, particularly how individuals often recognise the unhelpful nature of their anxious thoughts but have difficulty controlling or preventing them [22].

Factors important for building supportive relationships

A number of key factors emerged as being crucial for the development of a supportive relationship, both with family and professionals. The majority of participants made reference to a need to feel understood by both parents/caregivers and professionals, whilst feeling they could discuss issues relating to anxiety without feeling judged or burdensome. This supports well-established findings about the positive effect therapist empathy has on the therapeutic alliance [23]. The belief that people do not understand is likely to impact on the development of peer relationships and anxiety about being rejected. For some participants this was grounded in prior experience and therefore understandably increased their anxiety about forming friendships in the future. In addition it is clear that feeling understood plays a significant role in the child-parent relationship with mothers being viewed as a more effective source of support for anxiety than fathers who, in this sample, were described as less available.

Limitations and Areas for Future Research

The present study is not without its limitations. Firstly, the small sample

size limits generalisability however, the findings closely map onto previous research [15], which suggests some degree of generalisabilty. Secondly, the ethnic diversity of the sample was restricted and therefore findings may not represent different cultural backgrounds. Finally, whilst great care was taken to ensure participants had significant difficulties with anxiety through clinical and parental judgement, no standardised assessments were used to validate or measure this.

The results of the present study represent the first attempts to provide insight into the experience of anxiety in youth with ASD. Future research may wish to use similar methodologies in order to investigate whether these findings differ across specific ASD diagnoses. In addition, an interesting finding was how well participants described their physical symptoms of anxiety, lending support to the suggestion by Grondhuis & Aman [7] that capturing the physical expression of anxiety in ASD would be a helpful and viable addition to current assessments. Future research could also focus on how youth with ASD experience specific anxiety disorders such as OCD. This would inform assessment and differential diagnosis, something that at present is clinically challenging due to symptom overlap between the two disorders.

Conclusions

The way participants respond to their ASD diagnosis can contribute to social anxiety relating to possible rejection by peers. Professionals need to

consider this during the assessment and diagnostic process and provide support to the individual about how to disclose their diagnosis to others and manage feelings associated with an awareness of being different. Given the link between social skills deficits and anxiety reported by participants here, interventions would be best placed to target these deficits given the likely circular relationship between these factors [24].

It is clear there is a lack of awareness of the long-term negative effects of using avoidant-based strategies. Interventions need to include education around the mechanisms underlying the development and maintenance of anxiety so individuals can improve their awareness and develop more effective long-term strategies. Evidence suggests that exposure and response prevention (ERP) techniques, are effective when treating anxiety disorders such as OCD in youth with ASD [25, 26] and could be a useful approach when tailoring interventions.

Some participants spoke about their father's lack of understanding of their difficulties, which can lead to a less supportive relationship with regards to their difficulties. Services should attempt to include fathers in both the assessment, diagnostic and follow-up process to increase their understanding of their child's difficulties. Given that most participants reported relying heavily on their mothers to provide specific support in times of anxiety, teaching fathers strategies related to both anxiety and ASD to support their child, may help decrease potential care-giver burden in mothers. This could be achieved through home-based treatment

approaches that are more flexible allowing for work commitments.

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References

1. World Health Organization (WHO) report by the secretariat. (2013). Comprehensive and coordinated efforts for the management of autism spectrum disorders. Retrieved 7th April 2014 from http://apps.who.int/gb/ebwha/pdf_files/EB133/B133_4-en.pdf.

2. American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th, text rev). Washington, DC: American Psychiatric Association.

3. Ghaziuddin, M. (2002). Asperger's syndrome: Associated psychiatric and medical conditions. *Focus on Autism and Other Developmental Disabilities, 17,* 138-144.

4. Strang, J. F., Kenworthy, L., Daniolos, P., Case, L., Wills, M. C., Martin, A., et al. (2012). Depression and anxiety symptoms in children and adolescents with autism spectrum disorders without intellectual disability. *Research in Autism Spectrum Disorders, 6,(1)*, 406-412.

5. Mannion, A., Leader, G., & Healy, O. (2013). An investigation of comorbid psychological disorders, sleep problems, gastrointestinal symptoms and epilepsy in children and adolescents with autism spectrum disorder. *Research in Autism Spectrum Disorders, 7*, 35-42.

6. White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in Children and Adolescents with Autism Spectrum Disorders. *Clinical Psychology Review, 29(3)*, 216-229.

7. Grondhuis, S., & Aman, M. (2012). Assessment of anxiety in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders, 6*, 1345-1365.

8. Bellini, S. (2004). Social skill deficits and anxiety in high-functioning adolescents with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, *19***,** 78–86.

9. Leyfer, O. T., Folstein, S. E., Bacalman, S., Davis, N. O., Dinh, E., Morgan, J, et al. (2006). Comorbid psychiatric disorders in children with autism: Interview development and rates of disorders. *Journal of Autism and Developmental Disorders, 36*, 849-861.

10. Attwood, T. (2000). Strategies for improving the social integration of children with Asperger syndrome. *Autism*, *4*, 85-100.

11. Davis, T .E ., Moree, B. N., Dempsey, T., Reuther, E. T., Fodstad, J. C., Hess, J .A., et al. (2011). The relationship between autism spectrum disorders and anxiety: the moderating effect of communication. *Research in Autism Spectrum Disorders, 5***,** 324-329.

12. Meyer, J. A., Mundy, P. C., Vaughan Van Hecke, A., & Durocher, J. S. (2006). Social attribution processes and comorbid psychiatric symptoms in children with Asperger syndrome. *Autism*, *10*, 383-402.

13. Bellini, S. (2006). The development of social anxiety in adolescents with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, *21*, 138-145.

14. Gilliot, A., & Standen, P. J. (2007). Levels of anxiety and sources of stress in adults with autism. *Journal of Intellectual Disabilities, 11***,** 359–370.

15. Trembath, D., Germano, C., Johanson, G., & Dissanayake, C. (2012). The experience of anxiety in young adults with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, *27(4),* 213–224.

16. Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3(2),* 77-101

17. Smith, J. A., & Osborn, M. (2003). *Interpretative phenomenological analysis*. In J. A. Smith (Ed.), Qualitative Psychology: A Practical Guide to Methods. London: Sage.

18. Shinebourne, P. (2011). Interpretative Phenomenological Analysis. In N. Frost (ed). *Qualitative Research Methods in Psychology: Combining Core Approaches.* Open University. p.44-65.

19. Smith, J. A., Flowers, P., & Larkin, M. (2009). Interpretive phenomenological analysis: Theory, method, and research. London: Sage.

20. Banik, B., J. (1993). Applying triangulation in nursing research. *Applied Nursing Research*, *6(1),* 47-52.

21. Williams, C. J., Richards, P., & Whitton, I. (2002). *I'm not supposed to feel like this.* London: Hodden and Stoughton.

22. Wells, A. (1997). Cognitive Therapy of Anxiety Disorders: A practice Manual and Conceptual Guide. Wiley & Sons: West Sussex.

23. Lynch, M., M. (2012). Factors influenicing successful psychotherapy outcomes. *Master of Social Work Clinical research Papers, 57*.

24. Deramus, M. K. (2009). Repetitive Behaviours and Anxiety in Children with Autism Spectrum Disorder (Doctoral Dissertation). Retrieved from ProQuest Dissertations and Theses Database.

25. Lehmkuhl, H., Storch, E., Bodfish, J., & Geffken. (2008). Brief Report:

Exposure and Response Prevention for Obsessive Compulsive Disorder in a 12-year-old with Autism. *Journal of Autism and Developmental Disorders, 38*, 977-981.

26. Nadeau, J., Arnold, E. B., Storch, E. A., & Lewin, A. B. (2014). Family cognitive-behavioural treatment for a child with autism and co-morbid obsessive compulsive disorder. Clinical case studies, *13(1)*

Empirical Paper Appendix 1

Table 1: Participant characteristics

Pseudonym	Age	Gender	Diagnosis	Support previously received for anxiety	Current education
Katie	15	Female	Asperger's	School counselling	High school
Sarah	18	Female	Autism	None	College
Emma	15	Female	ASD and ADHD	School counselling	High school
Jane	16	Female	ASD	1:1 CAMHS therapy	College
Daniel	14	Male	Asperger's	None	High school
Simon	17	Male	Asperger's	Group and 1:1 CAMHS therapy	High school
Harry	13	Male	ASD	1:1 CAMHS therapy	Home schooled

Empirical Paper Appendix 2

Semi-structured interview schedule

GIG CYMRU NHS WALES
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Interview protocol for participants with ASD and anxiety related difficulties.

Prior to commencing interview session

- Introduce yourself.
- Remind participants that the interview will be recorded, check that it is still ok to do this
- Remind participants of confidentiality and that any use of their data will not identify them as individuals.

Introductory questions to develop rapport and gain background information:

Initial questions to generate hobbies/interests and establish rapport
Questions include – What year are you in at school?
What is your favourite subject?
What is your favourite TV programme?
What do you like doing after school?

(The wording of questions will be adapted slightly depending on whether the individual is currently receiving support for anxiety or has done so in the past and is therefore responding retrospectively. In addition the term ASD may be adapted to incorporate the individuals preference e.g. ASD or Autism)

ASD and anxiety

So I'm here to ask you questions about your ASD, and how it effects you, and would like to know when were you told that you had ASD?

1. How did you feel when you received your diagnosis of ASD?

2. What words or images come to mind when you think of ASD?
   Prompt – Do you have a nickname for it?

IF they mention anxiety then ask 'how long have you been having anxious feelings?'
If they do not mention anxiety then prompt 'so I have come to see you because my research is about people with ASD having anxious feelings, do you have anxious feelings sometimes?'

How did you get help with anxiety, did you talk to your family/carers/school about it or did they speak to you?

1. In your own words, what does the word anxiety mean to you?
   Prompt – what words/images come to mind? do you have a nickname for when it? how do you feel about having anxiety difficulties as well as ASD? how would you you define it?

2. How often during a day are you anxious?
   Prompt – Are there certain times of the day when you are more anxious?

3. What does anxiety feel like to you?
   Prompt – how does it make your body feel? Do you get tense? Where in the body do you get tense? Prompt: Tummy, shoulders etc.

4. When you are anxious, does it stop you from doing anything you would like to do?

5. How does anxiety affect you at school or college?

6. How does anxiety affect you at home?

7. How does anxiety affect your friendships/relationships

8. Ask Only if they work: How does anxiety affect you at work?

9. What things make you feel anxious?
   Prompt – are there certain things that trigger anxiety more than others? Are there certain people, places, situations that make you feel more anxious?

Identity

1. How would you describe yourself as a person?
   Prompt: What sort of person are you? Most important characteristics: happy, moody, nervy.

2. Has having ASD and anxiety difficulties made a difference to how you see yourself?
   Prompt – was there a time that you can remember before anxiety became such a difficulty, if so how did things change

3. What about the way other people see you?
   Prompt: members of your family, friends? changed?

4. Does anxiety effect your confidence/how you see yourself?

Coping with anxiety

1. Do you worry about having anxiety?

2. When you feel anxious, what do you do to make it better?
   Prompt – some people have relaxation techniques such as meditation or breathing, some people use distraction?

3. Are there particular people that you go to for help when you are anxious? What is it about these people that you find helpful when you are anxious? **OR** if no-one, do you think this might help? Why, why not?

Support received for anxiety

1. What support have you received/ or are currently receiving for your anxiety?

2. How often did you see them and where?

3. How do you feel about the support you have had/are having for anxiety?
   Prompt – would you recommend this to others, did it help or not?

4. Who do you remember working with? Did you like them/were they helpful?

5. Did you understand what they were doing?

6. Did getting help from someone for anxiety problems change the way you thought about yourself?
   Prompt – did it make you relieved that you were getting help, sad, embarrassed, angry

Additional filler questions may be required to expand some answers.

Examples are:

- You mentioned…….earlier, could you tell me more about this?
- We have talked about this already but is there anything you would like to add?

Thank participant for their time

Empirical Paper Appendix 3

Table 2: Main themes with corresponding subthemes

Main Theme	Sub-theme
The impact of anxiety	Immediate effects of anxiety
	Causes of anxiety
Managing anxiety	Avoidance/escape
	Distraction
	Taught techniques
	Hyper-vigilance of self and others
	Management of routines: The double edged sword of ASD
Navigating relationships	Home life
	"Mums been like a rock to me":Parental relationships
	Professional supportive relationships
	Disclosing an ASD diagnosis to others

SECTION 3: A review of the overlapping psychopathology in youth with Autism Spectrum Disorder (ASD) and Obsessive Compulsive Disorder (OCD).

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A review of the overlapping psychopathology in youth with Autism Spectrum Disorder (ASD) and Obsessive Compulsive Disorder (OCD).

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Title

A review of the overlapping psychopathology in youth with Autism Spectrum Disorder (ASD) and Obsessive Compulsive Disorder (OCD).

Lay Abstract

Thoughts and behaviours seen in Obsessive Compulsive Disorder (OCD) can appear similar to certain behaviours and thoughts in Autism Spectrum Disorders (ASD). Often such similarities can mean that professionals working with young people may overlook OCD, making assumptions that such behaviours are all due to ASD. This review highlights how ASD and OCD are different and guides professionals in selecting appropriate assessments and treatments for youth where ASD or OCD is a concern. 15 papers were reviewed and a number of findings emerged. Firstly, the type and number of obsessive thoughts differed between those youth with ASD and those with OCD. Those with OCD appeared to have more obsessions than those with ASD. Furthermore the purpose of particular behaviours appeared to be different between youth with ASD and OCD. More specifically repetitive behaviour was seen as being pleasurable for those with ASD but not OCD. A second finding was that assessments should cover a variety of areas in order for them to be comprehensive. Finally Cognitive Behavioural Therapy (CBT) for OCD in youth with ASD should be used, ensuring the family is involved to help support the young person through treatment. Further suggestions for developing clinical practice are discussed, as are ideas for future research.

Scientific Abstract

The obsessive thoughts and compulsive behaviours associated with Obsessive Compulsive Disorder (OCD) can be considered similar in presentation to core features of Autism Spectrum Disorders (ASD). This overlap can result in clinicians failing to recognise the presence of a comorbid anxiety disorder, such as OCD, in youth with ASD. The aims of the current review are to highlight ways in which ASD and OCD can be differentiated in youth, review the literature for the specific assessment of OCD in youth with ASD and finally, to review OCD-specific treatment for youth with ASD. Comprehensive literature searches were completed across three databases; Medline, Embase and PsycINFO, resulting in 15 papers eligible for review. Findings suggested there were significant differences in the number and type of obsessions and compulsions between ASD and OCD and the function of behaviour. In conclusion, it is recommended that assessments should focus on a variety of areas including executive functioning, obsessive-compulsive behaviour, repetitive behaviour and impact on functioning, to be fully comprehensive. Finally, modified Cognitive Behavioural Therapy (CBT) including exposure and response prevention, with an emphasis on involving the family around the young person, resulted in positive outcomes. Clinical implications include raising awareness within child services of the significant similarities between the two disorders, suggesting that assessment of comorbid anxiety disorders be routinely included alongside ASD assessments.

Key words: Children; adolescents; Autism Spectrum Disorder (ASD); Obsessive Compulsive Disorder (OCD); obsessions; compulsions, repetitive behaviour.

Introduction

Autism Spectrum Disorder (ASD) is a collection of childhood disorders characterised by marked impairments in social interaction and communication, repetitive behaviour and restricted interests (American Psychiatric Association, 2000). Obsessive Compulsive Disorder (OCD) is characterised by the presence of recurrent and persistent intrusive thoughts, impulses or images (obsessions) that cause marked anxiety or distress. Compulsions are behaviours that arise as a means to alleviate such distress (American Psychiatric Association, 2000). Both ASD and OCD have restricted behaviour as part of their diagnostic criteria (Francis et al, 2014), with ritualistic and rigid compulsions being defined in OCD and restricted repetitive behaviour including stereotypy and insistence on sameness, being defined in ASD (Lewis & Kim, 2009).

Taking the diagnostic criteria for both disorders into account one can see similarities. Intrusive obsessional thoughts in OCD bear a similarity to the cognitive rigidity and insistence on sameness commonly seen in ASD. Compulsive behaviour in OCD can also resemble restricted repetitive behaviour and stereotypy seen in ASD (Fischer-Temworth & Probst, 2009). It is important to understand how the two disorders differ in order for clinicians to make a differential or comorbid diagnosis, thus avoiding over diagnosing OCD in ASD or misdiagnosing comorbid OCD due to diagnostic overshadowing of ASD (Mason & Scior, 2004).

Findings suggest that aggressive and somatic obsessions and repeating, checking and counting compulsions are more frequently found in adults with OCD when compared to adults with ASD; whereas adults with ASD demonstrate more hoarding, touching and tapping behaviours than those with OCD (McDougle et al; 1995; Russell et al; 2005). These findings suggest that certain types of repetitive thoughts and behaviour can distinguish between adults with ASD and those with OCD. However the majority of the McDougle et al. (1995) sample had intellectual disabilities and therefore findings must be interpreted with caution when making comparisons to non-intellectually disabled samples. This is because McDougle et al. (1995) used self-report measures and intellectual functioning has been found to impact on the ability to report on one's own behaviour accurately.

OCD symptoms are generally characterised as being ego-dystonic, with a need to reduce and alleviate anxiety through compulsions. ASD symptoms are considered ego-syntonic, preferred or pleasurable (Fischer-Temworth & Probst, 2009). However this has been debated as individuals with ASD may lack the insight to reflect on their internal experiences thus making it difficult to confirm this distinction (Baron-Cohen, 1989). Individuals with ASD can also often perform certain behaviours to alleviate anxiety, which is diagnostic in OCD (Joliffe et al, 1992) and so again makes the ego-syntonic/dystonic distinction difficult to confirm.

According to a recent review of all anxiety disorders diagnosed in youth with ASD, OCD is the second most common with rates ranging from 17%-37% (Rudy et al, 2013). This is supported by cross-cultural data, which found the most common anxiety disorder was OCD (55%) in a sample of children with ASD from three Arab countries (Amr et al, 2012). Prevalence of OCD differs according to ASD subtype, with individuals with autism reporting more OCD symptoms than those with Asperger's. This is in contrast to literature on overall anxiety, which suggests individuals with Asperger's have more anxiety than those with Autistic Disorder (White et al, 2009).

There are currently no recommended guidelines specifically on how to assess or treat youth with comorbid ASD and OCD (ASD + OCD). Grondhuis and Aman (2012) conducted a systematic review of broad anxiety assessments for youth with ASD. They found ten assessments were most commonly used over a 10-year period, however only three had the capability to assess OCD in ASD in youth and only a small minority were empirically derived using ASD samples. Therefore they recommended more research is required to provide psychometric evaluation of assessments intended for use with this population, using ASD samples. Given this it seems appropriate to review OCD-specific assessments that have been psychometrically evaluated using ASD samples, as there are currently no reviews that focus on this. This would help guide clinicians in selecting such assessments when working with people with ASD + OCD.

There is growing evidence that CBT, with modifications appropriate to developmental level, is effective for youth with ASD, in particular when treating anxiety (Reaven & Hepburn, 2003). The use of exposure and response prevention (ERP), exposing individuals to anxiety provoking situations whilst preventing their avoidance of such, the use of in-vivo practice and developing effective coping skills, are key to this approach (Rudy et al, 2013). The majority of studies and reviews focus on a broad range of anxiety disorders and there are no reviews of treatment with a sole focus on youth with ASD + OCD. Therefore given the prevalence of ASD + OCD in youth, it seems appropriate that the evidence is reviewed in order to help provide guidance for clinicians working with these individuals.

There are three aims to this review; 1) To summarise evidence outlining the overlapping characteristics and psychopathology of OCD and ASD in youth, whilst describing factors that may help clinicians differentiate between the two, 2) To review evidence focusing on OCD-specific assessment for youth with ASD, to help guide clinicians when working with such comorbidity, 3) To review evidence for treating ASD + OCD in youth.

Method

The present review was approached systematically. PsycINFO, Medline and Embase were reviewed in March 2014. Five subject areas were covered using both subject headings and/or keywords as search terms. The first included the subject heading “Autism” (including Pervasive Developmental

Disorder) combined with keywords "ASD", "Autis*", "Asperger*", and "Kanners" using the OR function. The second area included the subject heading "Diagnosis" combined with keywords "case formulation" and "differential diagnosis" using the OR function. The third area included the subject heading "Obsessive Compulsive Disorder" combined with keywords "Ritual*", "Anancastic", "Anankastic" and "OCD" using the OR function. The fourth area included the keywords "treatment" and "intervention" combined using the OR function. The final included the keyword "assess*". This left five distinct subject areas, which were referred to as Autism, Diagnosis, OCD, Treatment and Assessment. Following the development of these subject areas they were then combined using the "AND" function in the following combinations to ensure a comprehensive search strategy. 1) Autism "AND" OCD; 2) Autism "AND" diagnosis "AND" OCD; 3) Autism "AND" OCD "AND" Treatment; 4) Autism "AND" OCD "AND" Assessment; 5) Autism "AND" OCD "AND" Treatment "AND" assessment; 6) Autism "AND" Diagnosis "AND" OCD "AND" Treatment; 7) Autism "AND" OCD "AND" Assessment "AND" Diagnosis and 8) Autism "AND" Diagnosis "AND" OCD "AND" Treatment "AND" Assessment. These search combinations were run across the three databases outlined above. This generated 1082 results. After duplications were removed 855 abstracts were reviewed by hand. Inclusion criteria were papers focusing on children and adolescent populations (1 to 17 years). Studies using mixed child and adult samples were included if they reported child/adolescent results separately. Papers were included if they investigated OCD and ASD using an ASD, OCD or ASD + OCD sample. Regarding treatment, studies focussing on youth with ASD +

OCD were included. With regards to assessment, only studies that focussed on OCD specific measures used within an ASD population were included. Only journals published from 2006 were reviewed in order to capture the most recent literature, which is within the recommended guidelines of 5-10 years for undertaking a review (Cronin et al, 2008). The exclusion criteria were: studies that had a specific focus on neurobiology and genetics, studies that only made comparisons between ASD or OCD to healthy controls, studies that only had adult populations and those that were not published in English.

Four studies were unavailable in English and three were unavailable due to access issues. Attempts were made to acquire these papers through liaison with local NHS library services and through Bangor University's library collection (using Shibboleth and Athens electronic accounts). However both organisations did not have access to the relevant journals and were unable to obtain these papers. Based on the above criteria, 15 papers were selected for review. Citation and reference searches were conducted on these papers and no further eligible studies were found.

Results

Fifteen studies met criteria, and are organised into three broad categories; characteristics and psychopathology, assessment, and treatment. Eight studies investigated characteristics and psychopathology in youth with ASD and OCD. Three investigated assessment tools with a specific focus on

psychometric properties and clinical utility. Four investigated treatment approaches specifically for ASD + OCD in youth. Studies reviewed are marked by a * in the reference list. See General Appendix 3 for summary table of studies reviewed.

Characteristics and Psychopathology

Of the studies reviewed two provide evidence that suggest high rates of OCD in those with ASD and high rates of ASD traits in those with primary OCD. Over half (57.1%) of 41 non-intellectually disabled children with ASD had clinical levels of OCD, as assessed by the Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS) (Deramus, 2009). ASD traits were found to be common in youth with primary OCD, following administration of the CY-BOCS and the high functioning Autistic Spectrum Screening Questionnaire (ASSQ) (Ivarrson & Melin, 2008). Whilst it is an advantage that Deramus (2009) used child self-reports she also reported that 75% of those with ASD met criteria for OCD using the Anxiety Disorders Interview Schedule (ADIS), parent version. However the validity of the ADIS for specifically assessing OCD symptoms in youth with ASD has not been established, therefore findings must be interpreted with caution. It is also important to note that without controlled epidemiological studies, prevalence data of OCD in those with ASD may reflect trends within particular regions at that time (Ivarrson & Melin, 2008), therefore further research is required.

Obsessions (frequency, type and severity)

Six studies investigated the similarities and differences between obsessions in OCD and ASD. Findings differ with regards to whether youth with OCD report more or fewer obsessions than those with ASD. When 36 age and gender matched youth with ASD + OCD, OCD and OCD + Tourette syndrome were compared on the CY-BOCS self-report, obsessions did not statistically differ between groups on frequency, severity or impact on life (Mack et al, 2010). However a limitation here is that IQ data was available for less than 50% of their sample, making it difficult to account for the influence of cognitive ability. In contrast, when Deramus (2009) used parent reports on a series of Obsessive/Compulsive and Repetitive behaviour measures in participants aged 7 to 17 years with ASD (49 parents) or OCD (12 parents), she found children with OCD had significantly more obsessions than those with ASD. A number of factors may have influenced these results, such as the large difference in sample size between the two groups as well as the sole use of parental reports, which may lack accuracy and could be influenced by factors such as parental stress.

Ruta et al. (2010) assessed 60 participants using the CY-BOCS, aged between 8 and 15 years. Participants were recruited from local mental health and school counselling services. Twenty had a diagnosis of OCD, 18 had a diagnosis of Asperger's and 22 were considered "healthy controls". They found that youth with OCD reported more contamination (a fear of being contaminated and/or contaminating others) and aggression (a fear of

harming self and/or causing harm to others) obsessions than the Asperger's group. Zandt et al. (2007) found youth with ASD reported fewer somatic obsessions (concern with illness, disease or an aspect of appearance) than those with OCD. This was supported by trends in the findings by Mack et al. (2010), however these were below statistical significance and so should be interpreted with caution. Another study reported that youth with OCD report more religious (concerns about morality) and health related obsessions than those with ASD (Deramus, 2009). Using the CY-BOCS to compare OCD symptoms across two groups (35 youth with OCD and 35 with ASD + OCD), Lewin et al. (2011) found that frequency of contamination and aggressive obsessions did not differ. However when these findings are combined with those of Ruta et al. (2010) it suggests these types of obsessions are more specifically associated with OCD.

In summary, there does not appear to be a significant difference in the *severity* of obsessions between the two disorders in youth (Lewin et al, 2011; Deramus, 2009). Ivarrson & Melin (2008) support this, reporting severity of OCD based on the CY-BOCS, did not predict the presence of ASD traits in a sample of 109 adolescents with a primary diagnosis of OCD. Evidence suggests youth with OCD typically report more obsessions across all categories on the CY-BOCS than those with ASD (Zandt et al, 2007; Deramus, 2009). Furthermore youth with OCD have different types of obsessions than those with ASD, with OCD reporting more contamination and aggression obsessions and more religious and health related

obsessions than ASD (Deramus, 2009; Ruta et al, 2010). Youth with ASD have fewer somatic obsessions than those with OCD (Zandt et al, 2007). However, severity of obsessions does not appear to differ between the two groups (Ivarrson & Melin, 2008; Deramus, 2009; Mack et al, 2010; Ruta et al, 2010; Lewin et al, 2011). Age was found to be a factor influencing the number of obsessions in youth with OCD, with older children self-reporting more obsessions on the CY-BOCS than younger children (Zandt et al, 2007).

Compulsions (frequency, type and severity)

Following the administration of the CY-BOCS and the Repetitive Behaviour Questionnaire (RBQ) to three groups of participants aged between 11-12 years (19 ASD, 17 OCD and 18 "typically developing"), Zandt et al. (2007) found youth with OCD were more likely to rate compulsions in all areas on the CY-BOCS than youth with ASD. In contrast Deramus (2009) found no difference in overall number of compulsions reported between the two disorders. It is likely this finding may have been skewed due to the significantly smaller OCD sample compared to her ASD sample (12 OCD, 49 ASD).

Deramus (2009) found that by using parental reports on the CY-BOCS, youth with OCD or ASD reported compulsions as similar in severity. Using the Repetitive Behaviour Scale (RBS), a parental measure developed for use with ASD, the only difference in severity was on the stereotyped behaviour and restricted behaviour severity scales, with youth with ASD scoring

higher on these than those with OCD. This could suggest these are specifically associated with ASD. No differences were reported across the self-injurious, compulsive, ritualistic and sameness behaviour subscales.

In the majority of studies there appears to be a difference between the two disorders in type of compulsion. Checking compulsions were higher in those with OCD than ASD (Ruta et al, 2010). Lewin et al. (2011) supported that those with ASD + OCD reported less checking, washing and repeating compulsions than those with OCD alone. This suggested checking compulsions are mitigated by the presence of ASD and may be associated with the underlying mechanisms of OCD. A limitation of Lewin et al. (2011) was that without a comparison group of youth with primary ASD it is difficult to make firm conclusions about the true overlap between ASD and OCD, especially comorbidity. In contrast to Ruta et al. (2010), Deramus (2009) found compulsion type did not differ between OCD and ASD, with both groups reporting checking, repeating and hoarding compulsions. However this particular finding was based on qualitative trends and not supported by statistical difference and therefore firm conclusions cannot be drawn.

In contrast to Lewin et al. (2011), Mack et al. (2010) also found by comparing scores on the CY-BOCS between youth with OCD and ASD + OCD, no significant differences emerged relating to specific compulsion frequency, except those with ASD + OCD reporting fewer games/superstitious compulsions than those with OCD. According to Mack

et al. (2010) these compulsions were considered more abstract reflecting core deficits with ASD in creativity and flexible thinking, thus explaining their lack of endorsement in ASD. Whilst participants recruited by Lewin et al. (2011) and Mack et al. (2010) can be considered similar in age and IQ, one significant limitation with Mack et al. (2010) was they did not use structured ASD diagnostic assessments as used by Lewin et al. (2011). Therefore rates of ASD in those with OCD may be underestimated making comparison across groups difficult.

In summary, research on compulsions is mixed, as some suggested those with OCD report more compulsions overall than those with ASD (Zandt et al, 2007) and others suggested no difference between the two disorders (Deramus, 2009). Findings also suggest parents of youth with OCD and ASD both rate compulsions with the same level of severity, however those with ASD appear to have more stereotyped and restricted behaviour characterised by repeated bodily movements and behaviour with a limited focus or range (Deramus, 2009). Those with OCD more frequently reported checking compulsions (Ruta et al, 2010), however others have found this not to be the case (Deramus, 2009). The use of comorbid samples highlighted those with OCD report more checking, washing and repeating compulsions than those with ASD + OCD (Lewin et al, 2011).

The function of behaviour

Four studies reviewed suggested that the function of behaviour, specifically the purpose and response to particular behaviours by the individual, should be closely considered when differentiating between OCD and ASD. Given both disorders include repetitive behaviour, the function of such behaviour may help classify whether it is compulsive and thus associated with OCD, or part of a set of behaviours such as ritualised, stereotyped or insistence on sameness, often viewed as core features of ASD.

Using the Repetitive Behaviour Scale (RBS) parent report measure, Deramus (2009) found parents of youth with ASD associated their child's stereotyped and restricted behaviours with higher rates of severity and distress than parents did on the same behaviour in their children with OCD. No other differences were reported. However the RBS does not allow further exploration of the experiential qualities and function of such behaviours and does not allow subjective experiences to be reported from an individual's own perspective. Rice (2009) addressed this by developing a way of assessing behaviour in youth with ASD and OCD by comparing parent, therapist and individual self-report versions of a repetitive behaviour scale. Scores were compared across 82 participants, 47 of whom were children. The total sample consisted of 25 with OCD, 23 with ASD and 34 with OCD + ASD. He identified four significant factors underlying the difference between compulsions and repetitive behaviour in OCD and ASD. These were "distressing", "intrusive", "pleasure-seeking" and "soothing". All

informants reported repetitive behaviour in ASD and ASD + OCD as being soothing, with repetitive behaviours in youth with OCD being intrusive.

One issue that affects consideration of the function of behaviour is that of insight and the ability to accurately reflect and report on one's own behaviour. Rice (2009) found moderate correlations between individual and parental reports on the intrusiveness of behaviour, suggesting the individuals' view on intrusiveness was supported by the views of their parents. Ratings of higher intrusiveness were associated with higher intellectual functioning, which may show a greater ability to reflect and evaluate one's own behaviour in these individuals. Correlations for the remaining subscales such as soothing and pleasure-seeking were low between individual and parent. This suggests parents had a different view than the individual themselves in these areas. Interestingly therapists rated the individual's compulsions as more soothing than the individual themselves or their parents. This may reflect that therapists often only view behaviour in a limited context, which may not reflect the true nature of the behaviour in other contexts such as the home where it may have more of an intrusive impact.

In summary repetitive behaviour such as stereotypy and restricted behaviour is considered more severe by parents of youth with ASD than those with OCD (Rice, 2009). More detailed exploration of the function of behaviour has allowed the quality of behaviour to be identified and it appears different between the two disorders. Parent, therapist and

individual reports suggested repetitive behaviour in OCD (compulsions) was considered intrusive. Repetitive behaviours such as stereotypy in those with ASD were considered pleasure-seeking (Rice, 2009). However some issues with insight were raised as correlations between individual, parent and therapist reports on whether behaviour was soothing, distressing or pleasure-seeking were found by Rice (2009) to be low. The only moderate correlation was found between parents and the individual on ratings of intrusiveness. This could suggest issues with accuracy of individual reports and may reflect underlying deficits in insight in youth with ASD and OCD and having difficulty reflecting on their own behaviour (Ivarrson & Melin, 2008; Ruta et al, 2010).

Executive Functioning

Of the studies reviewed, only one had a specific focus on the difference between OCD and ASD in youth with regards to executive functioning. Executive functioning refers to cognitive processes that are central in planning, organising and problem solving. Zandt et al. (2009) found those with ASD and OCD performed similarly on measures of executive functioning (inhibition, planning and organisation). However, they also found some differences between the groups, on measures of verbal fluency, with the ASD group performing lower on semantic and phonemic fluency. In addition when compared to controls the OCD group performed significantly worse on a task of inhibition (the walk, don't walk task). Parental reports on the Behaviour Rating Inventory of Executive Function

(BRIEF) executive functioning battery indicated children with ASD experienced significantly more difficulty on the initiate and monitor scales than those with OCD. The relationship between the BRIEF and more established measures of executive functioning is considered weak, suggesting the BRIEF may be assessing something other than executive functioning, such as parental concern and thus may confound these results (Zandt et al, 2009).

Assessment

This section of the review focuses on OCD-specific assessments for youth with ASD, to determine their utility in assessing comorbidity and measuring change following treatment. It is important to gain insight into this so clinicians can accurately assess two disorders with similar presentations. Three studies meeting the inclusion criteria were found, all focusing on developing the psychometric properties of the CY-BOCS for youth with ASD.

The CY-BOCS is a commonly used assessment tool to detect the presence, type, and severity of obsessions and compulsions in youth aged 8 to 17 years. The assessment is divided into two sections with a 70-item symptom checklist (divided across obsessions and compulsions), a 10-item symptom severity rating scale (5 for obsessions and 5 for compulsions) and a semi-structured interview that allows for more in-depth exploration of specific aspects of such symptoms. Ratings for each part of the assessment rely on

the responses of the individual in conjunction with clinical judgement and observations during the assessment made by the clinician. It is advised that supportive information is sought from parents or carers to help provide a thorough assessment of the individual's presentation. Symptoms are identified and organised to help inform treatment goals and a composite score is generated to evaluate the overall level of severity of OCD for the individual.

Scahill et al. (2006) pooled data from 172 medication-free children enrolled in two medication based randomised controlled trials (Risperidone and Methylphenidate). 152 had a diagnosis of autism, 6 had a diagnosis of Asperger's and 14 had a diagnosis of Pervasive Developmental Disorder-not otherwise specified (PDD-NOS). IQ varied above and below 70. Prior to the trials the CY-BOCS was modified for use with children with PDD (CY-BOCS PDD). The obsessions checklist and severity scales were removed due to the assumption that youth with PDD (predominantly Autistic in this case) are unable to accurately reflect or identify their internal thought processes due to language impairment. Compulsion checklists and severity scales were extended to include repetitive behaviours commonly found in children with PDD, with wording changed to allow for parental response. The assessment was administered to parents/caregivers at baseline and several points throughout the trials. Scahill et al. (2006) found the modified measure had excellent inter-rater reliability, with a Cronbach's alpha of 0.85, suggesting high internal consistency, which was maintained across IQ level. With relation to

sensitivity to change they noted that in the Risperidone medication trial the CY-BOCS PDD accurately detected change throughout the trials, providing support for its use as an outcome measure for treatment. A limitation here is that assumptions have been made on behalf of the researchers that all those with a diagnosis of PDD (which in their study included 6 with AS) have language impairments that preclude the ability to identify obsessions. However language impairment is only part of the diagnostic criteria for AD and not AS therefore the assessment developed here may not fully capture the obsessive-compulsive symptoms in those with AS.

Scahill et al. (2014) extended their previous findings and examined data across three controlled studies (Risperidone, Methylphenidate and Risperidone and/or 6 months parent training) where youth with ASD (291) were recruited. Approximately 50% of this sample were intellectually disabled. Using the CY-BOCS PDD (now termed CY-BOCS ASD), Principal Component Analysis revealed 5 components provided the best classification of repetitive behaviours in youth with ASD (Hoarding/Ritualistic behaviour, Sensory/Arranging, Sameness/Self-Injurious behaviour, Stereotypy and preoccupation). In addition each of these correlated well with associated scales on other established measures such as the Aberrant Behaviour Checklist (ABC) and Vineland Adaptive Behaviour Scale. Scahill et al. (2014) also found high internal consistency (0.82), matching their previous findings in 2006.

Wu et al. (2014) assessed the psychometric properties of the original CY-BOCS, administering it to 46 youth with ASD and average or higher intellectual functioning, following completion of a manualised 16 session behavioural program for anxiety. All participants scored above the normal range on the CY-BOCS suggesting the presence of OCD. They concluded the CY-BOCS had good internal consistency (0.81) and convergent validity with assessments such as the Vineland Adaptive Behaviour Scale, supporting Scahill et al. (2006) and Scahill et al. (2014). The CY-BOCS demonstrated treatment sensitivity following Cognitive Behaviour Therapy (CBT), with significant reductions in obsession and compulsion severity post-treatment (Wu et al, 2014). Although they were fairly comprehensive in their psychometric analysis of the CY-BOCS, factor structure and test-retest reliability were not assessed. Without this information it is difficult to confidently establish the most significant underlying factors applicable to these participants and establish stability over time.

In summary, the CY-BOCS is a reliable and valid assessment sensitive to treatment change, for high functioning youths with ASD (Scahill et al 2006; Scahill et al, 2014; Wu et al, 2014). The CY-BOCS-ASD is more appropriate for youth with ASD and intellectual disability, as it focuses more on the behavioural aspects of OCD (Scahill et al, 2006; Scahill et al, 2014).

Treatment

The final section of this review focuses on treatment specifically developed for ASD + OCD in youth. Four of the studies reviewed had a sole focus in this area, using a single case-design. Two studies addressed the effectiveness of medication on people with ASD + OCD (Sasayama et al, 2009; Celik et al, 2011). Two studies investigated the efficacy of CBT specifically for people with ASD + OCD (Lehmkhul et al, 2008; Nadeau et al, 2014).

Celik et al. (2011) found Aripriprazole, an atypical antipsychotic, was effective in treating symptoms of OCD and core social deficits in a 15-year-old boy with ASD. The CY-BOCS total score of 31 and parental interview indicated severe impairment with symptoms of OCD at the start of treatment. Aripriprazole was trialled for 14 days. After treatment, OCD symptoms reduced to mild impairment along with improvements in social reciprocity and eye contact. Scores on obsession sub-scales showed the greatest improvement when compared to compulsions. Whilst the single case design is an obvious limitation with its lack of generalizability, these initial findings are promising in the treatment of severe OCD in youth with ASD. Another important finding was that whilst behaviour improved, the guilt associated with such behaviour remained; suggesting medication alongside psychotherapeutic approaches such as CBT may be required.

Sasayama et al. (2009) provides evidence that selective serotonin reuptake inhibitors (SSRI) in particular Paroxetine is an effective treatment for use in youth with ASD and comorbid OCD. Using a single case design, they reported that following 8 weeks of Paroxetine the CY-BOCS score of a 15 year old girl with ASD and comorbid OCD reduced from an "extreme" score of 40 down to 14, which is considered "mild". Although obsessive tendencies were present throughout childhood, the onset and diagnosis of OCD, namely a contamination fear with contamination-related checking behaviour, was recent, at the age of 15 years. Whilst contamination fears reduced, obsessional tendencies that were present prior to the onset of OCD were still present at 6 month follow up which led the researchers to conclude that Paroxetine may not address obsessionality that is associated with fundamental aspects of ASD. It should also be noted that the researchers used Paroxetine as an adjunct to behaviour therapy and therefore it is difficult to conclude the mechanism of change. In addition the researchers only report reductions in obsessional thinking and do not report whether changes in compulsive behaviour were seen following treatment. It is therefore difficult to conclude whether such medication is effective in reducing such behaviour.

CBT with appropriate adaptations has often been shown to be effective in treating a variety of conditions in youth with comorbid conditions alongside ASD (Reaven & Hepburn, 2003). However there is very little research on the use of CBT with a sole focus on youth with comorbid ASD and OCD.

Lehmkhul et al. (2008) present a case where adapted CBT based on previously published research by March and Mulle (1998) was effective in treating OCD in a twelve-year-old boy with ASD, across ten sessions. CBT included two key components; Exposure and Response Prevention (ERP) and the development of a hierarchy of symptoms to target. It was noted that due to difficulty identifying obsessions, cognitive restructuring and imagined exposure were suspended, with extra time spent developing coping statements and identifying feelings of distress. A significant decrease on the CY-BOCS total score was found, from moderately severe to within normal limits. These gains were maintained at 3 months. It must be noted that the child's difficulties relating to ASD were considerably reduced due to high levels of early intervention received, therefore these findings do not provide information on the effectiveness of CBT in youth with more severe impairments relating to ASD. Importantly, particular emphasis was placed on the wider system around the child, with parents being heavily involved in treatment to minimise accommodation of behaviour and enhance homework completion.

In line with Lehmkhul et al. (2008), Nadeau et al. (2014) provide evidence for the need to include the family around the child with ASD and comorbid OCD. Using a single case design Nadeau et al. (2014) showed that a family-based CBT intervention with ERP was effective in reducing the moderate levels of obsessive- compulsive symptoms in a 9 year old boy with ASD and OCD. Sixteen sessions of a manualised intervention designed to address key

areas such as affective education, coping skill development and the generation of an OCD hierarchy were delivered across 21 weeks. Sessions were tailored to provide education to parents around issues relating to reassurance giving and accommodation as well as the generation of a rewards system where consistency between parents was essential. Nadeau et al. (2014) found that inconsistency of parents to facilitate opportunities for their child to habituate to anxiety rather than escaping the situation was a main factor that obstructed treatment. In addition parents were providing rewards to quickly alleviate their child's anxiety, which negatively reinforced his behaviour. The researchers therefore emphasise that time be spent specifically with parents to address this. The CY-BOCs score at post treatment suggested a complete remission of his OCD diagnosis (initial scores of 27 reduced to 0) which was supported by a significant reduction in OCD symptoms as assessed by the Anxiety Disorders Interview Schedule parent measure. Social functioning also appeared to show some improvement with social reciprocity and motivation increasing following treatment. One limitation of this study is that its design prevents the researchers from concluding whether such an approach would be as effective in an individual with more severe mood difficulties, challenging behaviour or intellectual disability. More research is therefore necessary to highlight the types of modifications that may be necessary here.

A notable limitation of both Lehmkhul et al. (2008) and Nadeau et al. (2014) is that their use of a single case design does not allow for

generalisabilty of their findings. However the results of these studies provide promising evidence that a flexible and adaptable approach to the delivery of CBT, incorporating the family system, can be effective in treating OCD (both obsessions and compulsions) in youth with ASD.

Discussion

To the authors knowledge this review is the first to focus specifically on the phenomenological overlap between OCD and ASD in children and adolescents to aid differential diagnosis, whilst providing information on assessment and treatment.

The evidence reviewed suggests that the most effective way to differentiate between OCD and ASD is through overall number and type of obsessions, as assessed using the CY-BOCS. Supporting findings from adult literature, (McDougle et al, 1995; Russell et al, 2005), youth with OCD appear to report more obsessions than those with ASD in particular those with OCD reporting more contamination, aggression, religious and health related obsessions than those with ASD (Deramus, 2009; Ruta et al, 2010).

In relation to behaviour research suggests that youth with ASD appear to have more stereotyped and restricted behaviour than youth with OCD (Deramus, 2009) with those with OCD more frequently report checking compulsions than those with ASD (Ruta et al, 2010). The use of comorbid

samples has highlighted that those with OCD report more checking, washing and repeating compulsions than those with comorbid ASD + OCD (Lewin et al, 2011). This may suggest that whilst those with ASD do exhibit checking behaviour, checking compulsions may be specifically associated to OCD in youth. One explanation for this may be the link between checking behaviour and pathological doubt in those with OCD. Individuals may doubt their memories of performing behaviour and thus need to repeat it (Ivarrson & Melin, 2008). However more research into this relationship is required as pathological doubt in OCD was also found to predict subclinical ASD traits in those with OCD (Ivarrson & Melin, 2008).

Of the evidence reviewed it is not clear whether there is a difference between overall number of compulsions between youth with OCD and ASD, however both report compulsions to be severe thus suggesting that a measure of severity alone may not be the best way to differentiate between OCD and ASD in youth (Deramus, 2009). However a number of studies used parent report to establish these findings and therefore can be criticised for lacking subjectivity. However, it could be argued that parents of youth with disabilities have a closer, more in tuned relationship than those without, due to increased levels of care and time spent together. They may therefore be better placed to report on their difficulties (Dewrang & Sandberg, 2011).

An explanation as to why those with comorbid OCD/ASD did not report some of the more classic compulsions (checking, washing and repeating) may reflect a difference in the typical obsessive-compulsive cycle between

the two disorders. Lewin et al. (2011) and Piacientini (2008) suggest that in OCD, compulsions are carried out due to the amount of fear evoked through obsessions. It may be that in ASD the same levels of fear do not arise in the same situations as in OCD (Lewin et al, 2011). This may also reflect underlying deficits in perception found to be in those with ASD that may inhibit the assessment or recognition of fear (Dewrang & Sandberg, 2011), thus resulting in different behaviours being endorsed.

Both those with OCD and ASD have specific deficits in executive functioning rather than global impairment (Zandt et al, 2007), which mirrors findings from adult literature (Anholt et al, 2010; Wakabayashi et al, 2012). When compared to youth with OCD, those with ASD had greater deficits in verbal fluency and concept generation, both of which require the generation of multiple responses (Zandt et al, 2009), which supports earlier findings by Turner (1999). This suggests youth with ASD may have greater difficulty in being able to self-cue and generate responses to help with performance than those with OCD, which may account for some of the difficulties seen in social situations in ASD and thus account for why parents rate them as having more difficulties.

For measures specifically designed to assess OCD, the CY-BOCS and the CY-BOCS ASD seem to be both valid for use with co-morbid ASD and OCD (Scahill et al, 2006; Scahill et al, 2014; Wu et al, 2014). The CY-BOCS-ASD is most suited for individuals with lower intellectual functioning, focussing more on behavioural aspects. The CY-BOCS is better suited for use with

higher functioning individuals. Both have the ability to measure treatment efficacy. One criticism of the anxiety assessments available for youth with ASD is that very few are normed using ASD samples (Grondhuis & Aman, 2011). The findings of Wu et al. (2014) therefore provide retrospective validity for any studies that have used the original CY-BOCS with youth with ASD, who have average or above intellectual functioning. However to the author's knowledge there are no published evaluation studies that conclude whether the use of the original CY-BOCS is psychometrically sound for youth with ASD who have an IQ below 70 and so the CY-BOCS ASD as developed by Scahill et al. (2006) and Scahill et al. (2014) may be more appropriate here.

SSRI's have been shown to be effective in the treatment of paediatric OCD (Geller et al, 2004) and also provide therapeutic benefits in youth with ASD (Kolevzon et al, 2006) suggesting a common relationship between the two disorders and serotonin regulation. Of the two studies reviewed here both SSRI (Paroxetine) and Antipsychotic (Aripriprazole) medications have been shown to be effective when treating youth with comorbid ASD and OCD (Sasayama et al, 2009; Celik et al, 2011). Both these studies suggest that these types of medications are both effective at treating the obsessions that are associated with OCD, but not the fundamental obsessionality associated with ASD (Sasayama et al, 2009). The studies reviewed do not provide evidence that SSRI's are effective in treating compulsive behaviour associated with OCD in youth with ASD, however Celik et al. (2011) do support the use of Aripriprazole in treating such behaviours. Findings from

both Celik et al. (2011) and Sasayama et al. (2009) lend support for a dual treatment approach where medication may be used as an adjunct for psychological therapy. Treatment gains for Paroxetine were found when weekly behaviour therapy was provided and because guilt associated with obsessions remained following treatment with Aripriprazole, individual therapy may be necessary to further explore the residual feelings that are often associated with OCD. Whilst the conclusions drawn here provide positive support for the use of medication when treating OCD in youth with ASD, the evidence presented relies solely on single case designs and therefore conclusions should be viewed tentatively and generalisabilty should not be assumed.

CBT with modifications appropriate to developmental level such as visual cue cards and concrete special interest related metaphors is useful when treating youth with comorbid OCD and ASD (Lehmkhul et al, 2008; Nadeau et al, 2014). The evidence reviewed suggested that treatment gains can be maintained up to 4 months following therapy. With this population it is important to consider the role of the family and for clinicians to provide tailored support and education specifically around the negative aspects of reassurance giving and accommodation (Nadaeu et al, 2014). Whilst none of the studies reviewed in the current paper report the inclusion of educational staff in their treatment, there is a legitimate case to be made for including them, as support needs to be consistent across different contexts to promote generalisation of skills developed within treatment.

Limitations of current review

The review has a number of limitations. Firstly studies often reported an "ASD" sample, which was made up of people with Autism, Asperger's and PDD-NOS without reporting results according to each diagnosis separately. Whilst these are currently conceptualised as existing on a spectrum, there are known differences between the presentations of each. The implications for this current review is that findings should be interpreted with caution as there may be subtle differences in how OCD overlaps which each ASD diagnosis which needs further exploration.

Secondly, whilst the author maintains that the search terms used generated a comprehensive and systematic review of the literature, it is noted that additional search terms such as "therapy" or "medication" may have yielded more results regarding treatment and intervention thus allowing for a more comprehensive review.

Thirdly, by only targeting studies that have a sole focus on the treatment of comorbid OCD and ASD in youth, it can be argued that studies were overlooked that address treatment for broad anxiety disorders that include a sub sample of OCD. However by including multiple anxiety disorders it becomes difficult to identify treatment factors and necessary modifications specific to OCD in order to help clinicians to tailor their approach when working with youth with ASD.

Clinical Implications and Areas for Future Research

The lack of significant difference in severity of both obsessions and compulsions between OCD and ASD is an important finding as it means that clinicians need to look past the most "severe" symptoms when establishing a diagnosis. People often present to services with the symptoms that are most debilitating or impairing and whilst it is obviously important to alleviate these, without a more detailed assessment other key aspects of symptoms may be overlooked.

The current review clearly highlights that the similarities and differences between OCD and ASD in youth span a variety of domains including obsessive-compulsive behaviour, restricted and stereotypic behaviour, and executive functioning. Therefore it is important for clinicians to ensure that a multi-dimensional approach to assessment is considered using specific assessments designed to target each of these when attempting to differentially diagnose OCD and ASD in youth. In addition it would also be useful for clinicians to include the young persons parents, health professionals and school/educational staff to ensure that assessments are comprehensive and consider a variety of contexts.

Rice (2009) found parent and child ratings were correlated in terms of how intrusive obsessions were. This is in contrast to findings that individuals with ASD lack the ability to describe their internal states (Baron-Cohen, 1989). Rice (2009) noted that on all other ratings for behaviour (soothing,

pleasure-seeking and distressing) correlations between parent and child were low. Parents may report the distressing quality of a behaviour when in fact the child may feel it is soothing. There are a number of implications here. Firstly is that insight needs to be assessed on an individual basis and not simply assumed as being lacking simply because a child has ASD. This will ensure that individuals get the opportunity to report on their own behaviour and its function thus preventing assumptions being made about what behaviour should be the target of treatment. For those that lack the insight to report on their behaviour clinicians may want to assess the impact behaviours have on functioning as by finding out how a behaviour impacts on a persons life may provide more insight into how they may experience a behaviour e.g. pleasure seeking versus distressing. Secondly understanding the function of behaviour will help guide clinicians in developing their formulation and understanding of the reported difficulties and to tailor their interventions. For some children the behaviour may be soothing or pleasurable, yet this same behaviour may be distressing for their parents. Therefore clinicians would need to be aware of this in order to focus and tailor their intervention appropriately, which in this case may be more systemic and family based rather than working with the children themselves.

One area for future research may be that more is needed to develop assessments specifically designed for youth with ASD, using ASD samples. This way accurate psychometric data can be established, allowing for norms to be generated, meaning more valid comparisons can be made

across groups. In addition for clinicians to accurately differentiate between OCD and ASD in youth, assessments should incorporate what is known from the literature regarding the significance of type and function of obsessions, compulsions and repetitive behaviour. Future assessments should also capture the physical aspects of OCD, something that is absent in current measures (Grondhuis & Aman, 2011). In addition, given the similarities and subtle differences between ASD and OCD, ASD assessments may need to be developed to incorporate an assessment of OCD. This will go someway to ensure that such comorbidities are not misdiagnosed as core aspects of ASD.

Only two studies focussing on psychological treatment were found, and they were both single case designs relating to CBT and youth with comorbid ASD and OCD. Whilst both these studies suggest the efficacy of CBT in this population their generalisabilty is limited and a need for more robust controlled trials involving larger samples is necessary. From searching the literature on adults with ASD one such study using a randomised control design involving a combined sample of older adolescents and adults suggested that CBT is effective at treating OCD in those with ASD (Russell et al, 2013). However Russell et al. (2013) did not separately report on the adolescent results therefore it remains unclear as to the effectiveness of CBT specifically for this population and what modifications may be necessary.

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References

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text revision). Washington, DC: Author.

Amr, M., Raddad, D., El-Mehesh, F., Bakr, A., Sallam, K., & Amin, T. (2012). Comorbid psychiatric disorders in Arab children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 6,* 240–248.

Anholt, G., Cath, D., van Oppen, P., Eikelenboom, M., Smit, J., van Megen, H., et al. (2010). Autism and ADHD Symptoms in Patients with OCD: Are They Associated with Specific OC Symptom Dimensions or OC Symptom Severity? *Journal of Autism and Developmental Disorders, 40,* 580-589.

Baron-Cohen, S. (1989). Are autistic children behaviourists? An examination of the mental-physical and appearance-reality distinctions. Journal of Autism and Developmental Disorders, 19, 579-600.

*Celik, G., Tahiroglu, A., Firat, S., & Avci, A. (2011). Aripiprazole Improved Obsessive Compulsive Symptoms in Asperger's Disorder. *Clinical Psychopharmacology and Neuroscience, 9(3),* 134-136.

Cronin, P., Ryan, F., & Coughlan, M. (2008). Undertaking a literature review: a step-by-step approach. *British Journal of Nursing, 17(1),* 38-43.

*Deramus, M. K. (2009). Repetitive Behaviours and Anxiety in Children with Autism Spectrum Disorder (Doctoral Dissertation). Retrieved from ProQuest Dissertations and Theses Database.

Dewrang, P., & Sandberg, A. (2011). Repetitive behaviour and obsessive-compulsive features in Asperger syndrome: Parental and self reports. *Research in Autism Spectrum Disorders, 5,* 1176-1186.

Fischer-Temworth, C., & Probst, P. (2009). Obsessive-compulsive phenomena and symptoms in Asperger's disorder and High-functioning Autism: An evaluative literature review. *Life Span and Disability, 12(1),* 5-27.

Francis, S. M., Kim, S-J., & Jacob, S. (2014). Restricted Repetitive Behaviours: Connections Between Autism Spectrum and Obsessive-Compulsive Spectrum Disorders. In Storch, E. A., & McKay, D. (Eds.), *Obsessive-Compulsive Disorder and its Spectrum: A Life-Span Approach* (pp.261-289). Washington, DC: American Psychological Association.

Geller, D. A., Wagner K. D., Emslie, G, Murphy, T., Carpenter, D. J., Wetherhold, E., et al. (2004) Paroxetine treatment in children and adolescents with obsessive-compulsive disorder: A randomized, multicenter, double-blind, placebo-controlled trial. *Journal of American Child and Adolescent Psychiatry. 43*, 1387–1396.

Grondhuis, S., & Aman, M. (2012). Assessment of anxiety in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders, 6,* 1345-1365.

*Ivarsson, T., & Melin, K. (2008). Autism spectrum traits in children and adolescents with obsessive-compulsive disorder (OCD). *Journal of Anxiety Disorders, 22*, 969-978.

Jolliffe, T., Lansdown, R., Robinson, C., (1992). Autism: a personal account. *Communication, 26*, 12–19.

Kolevzon A, Mathewson K.A, Hollander E. (2006). Selective serotonin reuptake inhibitors in autism: A review of efficacy and tolerability. *Journal of Clinical Psychiatry, 67*, 407–414.

*Lehmkuhl, H., Storch, E., Bodfish, J., & Geffken. (2008). Brief Report: Exposure and Response Prevention for Obsessive Compulsive Disorder in a 12-year-old with Autism. *Journal of Autism and Developmental Disorders, 38,* 977-981.

*Lewin, A., Wood, J., Gunderson, S., Murphy, T., & Storch, E. (2011). Phenomenology of Comorbid Autism Spectrum and Obsessive-Compulsive Disorders Among Children. *Journal of Developmental and Physical Disabilities, 23*, 543-553.

Lewis, M., & Kim, S. J. (2009). The pathophysiology of restricted repetitive behaviour. *Journal of Neurodevelopmental Disorders, 1(2),* 114-32.

*Mack, H., Fullana, M., Russell, A., Mataix-Cols, D., Nakatani, E., & Heyman, I. (2010). Obsessions and Compulsions in Children with Asperger's Syndrome or High-Functioning Autism: A Case-Control Study. *Australian and New Zealand Journal of Psychiatry, 44*, 1082-1088.

March, J. S., & Mulle, K. (1998). *OCD in children and adolescents: A cognitive behavioral treatment manual.* New York: Guilford Press.

Mason, J., & Scior, K. (2004). Diagnostic overshadowing amongst clinicians working with people with intellectual disabilities in the UK. *Journal of Applied Research in Intellectual Disabilities, 17***,** 85-90.

McDougle, C. J., Kresch, L. E., Goodman, W. K., Naylor, S. T., Volkmar, F. R., Cohen, D. J., et al. (1995). A case-controlled study of repetitive thoughts and behaviour in adults with autistic disorder and obsessive-compulsive disorder. *American Journal of Psychiatry, 152*, 772-777.

*Nadeau, J., Arnold, E. B., Storch, E. A., & Lewin, A. B. (2014). Family cognitive-behavioural treatment for a child with autism and co-morbid obsessive compulsive disorder. *Clinical case studies, 13(1),* 22-36.

Piacentini, J. (2008). Optimizing cognitive-behavioral therapy for

childhood psychiatric disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 47(5),* 481-482.

Reaven, J., & Hepburn, S. (2003). Cognitive-behavioural treatment of obsessive-compulsive disorder in a child with Asperger syndrome: a case report. *Autism, 7(2)*, 145-64.

*Rice Jr, R. H. (2009). The Repetitive Behaviour Spectrum: From Autism to Obsessive Compulsive Disorder (Doctoral Dissertation, University of Rochester).

Rudy, B. M., Lewin, A B., & Storch, E. A. (2013). Managing anxiety comorbidity in youth with autism spectrum disorders. *Neuropsychiatry, 3(4),* 411-421.

Russell, A.J., Mataix-Cols, D., Anson, M., & Murphy, D. (2005). Obsessions and compulsions in Asperger syndrome and high-functioning autism. *British Journal of Psychiatry, 186*, 525-528.

Russell, A., Jassi, A., Fullana, M., Mack, H., Johnston, K., Heyman, I., et al. (2013). Cognitive Behaviour Therapy for Comorbid Obsessive-Compulsive Disorder in High-Functioning Autism Spectrum Disorders: A Randomized Controlled Trial. *Depression and Anxiety, 30,* 697-708.

*Ruta, L., Mugno, D., Genitori D'Arrigo, V., Vitiello, B., & Mazzone, L. (2010).

Obsessive-compulsive traits in children and adolescents with Asperger syndrome. *European Child and Adolescent Psychiatry, 19,* 17-24.

*Sasayama, D., Sugiyama, N., Imai, J., Hayashida, A., Harada, Y & Amano, N. (2009). High-dose paroxetine treatment for an adolescent with obsessive-compulsive disorder co-morbid with Asperger's disorder. *Psychiatry and Clinical Neurosciences, 63(2),* 251.

*Scahill, L., Dimitropoulos, A., McDougle, C., Aman, M., Feurer, I., McCracken, J., et al. (2014). Children's Yale-Brown Obsessive Compulsive Scale in Autism Spectrum Disorder: Component Structure and Correlates of Symptom Checklist. *Journal of the American Academy of Child and Adolescent Psychiatry, 53(1),* 97-108.

*Scahill, L., McDougle, C. J., Williams, S. K., Dimitropoulos, A., Aman, M. G., McCracken, J. T et al. (2006). Children's Yale Brown Obsessive Compulsive Scale modified for pervasive developmental disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 45(9),* 1114-1123.

Turner, M. A. (1999). Generating novel ideas: Fluency performance in high functioning and learning disabled individuals with autism. *Journal of Child Psychology and Psychiatry, 40*,189–201.

Wakabayashi, A., Baron-Cohen, S., & Ashwin, C. (2012). Do the traits of autism-spectrum overlap with those of schizophrenia or obsessive-

compulsive disorder in the general population? *Research in Autism Spectrum Disorders, 6,* 717-725.

White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in Children and Adolescents with Autism Spectrum Disorders. *Clinical Psychology Review, 29(3)*, 216-229.

*Wu, M. S., McGuire, J. F., Arnold, E. B., Lewin, A. B., Murphy, T. K., & Storch, E. A. (2014). Psychometric Properties of the Children's Yale-Brown Obsessive Compulsive Scale in Youth with Autism Spectrum Disorders and Obsessive-Compulsive Symptoms. *Child Psychiatry and Human Development, 45,* 201-211.

*Zandt, F., Prior, M., & Kyrios, M. (2007). Repetitive Behaviour in Children with High Functioning Autism and Obsessive Compulsive Disorder. *Journal of Autism and Developmental Disorders, 37,* 251-259.

*Zandt, F., Prior, M., & Kyrios, M. (2009). Similarities and differences between children and adolescents with autism spectrum disorder and those with obsessive compulsive disorder: Executive functioning and repetitive behaviour. *Autism, 13(1),* 43-57.

SECTION 4: Contributions to Theory and Clinical Practice: A focus on service development – Assessment, post diagnosis and intervention

Contributions to Theory and Clinical Practice: A focus on service development – Assessment, Post-diagnosis and intervention

Introduction

The findings of the empirical paper "A qualitative analysis of the lived experiences of adolescents with Autism Spectrum Disorder (ASD) and comorbid anxiety difficulties" and the literature review focussing on the overlapping symptoms between ASD and OCD in youth, generated several clinical and research implications.

Participants in the empirical paper reported receiving a diagnosis of ASD could be either beneficial or anxiety provoking. Most reported an awareness of their diagnosis and felt it made them appear different to those around them, leading to anxieties about being judged or rejected. In contrast some participants said receiving their diagnosis provided an explanation for their difficulties, and therefore relief. In addition participants described how factors fundamental to their ASD (e.g. preference for routine and structure) helped them cope with everyday anxieties by using coping strategies such as writing lists. In contrast other core aspects of ASD (e.g. difficulty adapting to change and the unexpected) contributed to anxiety with individuals feeling they needed to plan for all aspects of life. Such an approach was often unsustainable and resulted in confusion and further anxiety. Finally, the empirical paper highlighted

participants frequently used avoidance-based techniques to manage anxiety, with little awareness of the negative aspects of this.

The literature review highlighted how the features of ASD and OCD in youth can be distinguished from each other, specifically regarding obsessions, compulsions and repetitive behaviour. In ASD and OCD there were high levels of obsessions, however those with OCD reported more than those with ASD, based on the Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS). In addition, type of obsession can be used to differentiate between the two disorders, with OCD reporting more contamination and aggressive obsessions. Furthermore the two disorders differed in terms of repetitive behaviour, in that those with ASD reported more stereotypic behaviour (e.g. hand flapping or rocking) than those with OCD. Checking behaviour was more specifically associated with OCD than ASD, potentially influenced by the presence of pathological doubt. The function of behaviour differed between ASD and OCD, with compulsive behaviour in OCD viewed as intrusive and repetitive behaviour in ASD viewed as pleasurable and soothing. In addition the literature review emphasised that including the family in treatment for anxiety, such as OCD, led to positive outcomes.

The most significant finding across both papers was that youth with ASD were significantly influenced by their relationships with others, in particular their family. Having a strong supportive parent during times of anxiety was beneficial in managing such difficulties. Inconsistencies in

parental response and a lack of understanding difficulties could be detrimental to progress in treatment and also contributory to anxiety.

These findings contribute to the theoretical understanding of anxiety in youth with ASD, highlighting that specific anxiety disorders, such as OCD, can be differentiated from ASD in the ways outlined above. In addition, the qualitative analysis showed that anxiety in youth with ASD affected most aspects of the participant's lives. Furthermore, certain thoughts around socialisation and hypothetical rumination were significant in causing anxiety.

Scope of the present paper

The findings of the empirical paper and the literature review highlighted three areas for further discussion 1) Assessing comorbidity in youth with ASD, 2) Post-diagnostic support, 3) Involving family in interventions and addressing avoidance-based coping. Each area is discussed with reference to the findings of both papers. Implications for clinical practice and research follow the presentation of each area. Directions for future research are proposed, followed by personal reflections on conducting this research project.

Assessing for comorbidity in youth with ASD

The literature review highlighted the type and overall number of obsessions and compulsions in addition to the function of compulsive/repetitive behaviour, can distinguish between ASD and OCD in youth. Current guidelines recommend the presence of comorbid anxiety disorders, including OCD, are considered during the ASD assessment process. However, little guidance is provided on how to do this. The literature review highlighted that multi-dimensional assessments should be used to prevent diagnostic overshadowing of ASD and from misdiagnosing OCD in ASD. Table 1 suggests possible assessments, which could be used to do this.

Table 1: Recommended assessments to be used when assessing for OCD in youth with ASD

Focus of Assessment	Assessment title	Brief description
Executive functioning	Behaviour Rating Inventory of Executive Function (BRIEF)	This assessment takes 15 minutes to complete and assesses executive function behaviours in the school and home environment
Obsessive Compulsive behaviour	The Children's Yale Brown Obsessive Compulsive Scale (CY-BOCS)	The CY-BOCS and CY-BOCS ASD (for those with lower intellectual functioning) is the most frequently used assessment for obsessions and compulsions in children using a checklist and questionnaire format. It includes both a parent and child report version.
Repetitive Behaviour	Repetitive Behaviour Scale (RBS)	The Repetitive Behaviour Scale (RBS) is a parent informed questionnaire intended to capture the breadth of repetitive behaviour in ASD.

In addition to the above conducting a functional analysis to further understand behaviour would be useful for individuals with lower intellectual functioning, who cannot provide the information themselves.

Implications for clinical practice

Given the above findings there are number of implications for clinical practice. Firstly, to raise awareness of the overlap between features of ASD and OCD in youth, dissemination of the literature review findings to those working in child services is necessary. This could be done through presenting at departmental/team meetings or providing summaries of the research to heads of department for them to disseminate within teams.

Secondly, clinicians should be appropriately trained in the administration, scoring and interpretation of assessments outlined in table 1. These should be considered during ASD assessments where the presence of OCD is suspected, to help with differentiation. Supervision agreements between staff within teams and a "train the trainers" approach would ensure appropriate training is shared at minimal expense.

Thirdly, whilst parents, therapists and the child themselves all viewed obsessions to be intrusive, correlations between the three informants differed significantly on whether a behaviour was viewed as distressing, soothing or pleasure-seeking. This is important for clinicians to consider as it has implications for assessment, formulation and intervention. Behaviour was sometimes viewed as pleasure-seeking or soothing by the individual but distressing or intrusive for the parent/carer. Therefore by being aware of this, clinicians can provide guidance for the parents/carer to better

support their child and manage their own distress, rather than working directly with the child.

Finally, clinicians should consider the wider system around the young person and where possible consult education staff when carrying out assessments. This will ensure assessments capture the presentation of OCD in a variety of contexts. Given the important role such staff play in the daily lives of youth with ASD, liaising with schools would better inform initial formulations of their difficulties. It would also help identify any information that may not be reported by parents, which can also inform assessment.

Post-Diagnostic work

Current guidelines developed by the National Institute for Health and Clinical Excellence (NICE CG128, 2011), for youth with ASD, provide clinicians with detailed guidance on how to complete comprehensive diagnostic assessments. However, NICE guidance on the delivery of post-diagnostic support is relatively vague, recommending diagnosis be communicated "sensitively" to children and families. They also recommend an appointment be given within six weeks following diagnosis, to provide clarification and further explanation. Current guidelines do not provide clinicians with specific advice on what types of post-diagnostic support are effective.

Recent audits within Child and Adolescent Mental Health Services (CAMHS) across North Wales revealed assessment and diagnosis, in particular post-diagnostic support, are inconsistent and require development. A thematic analysis of parental experiences of their child's ASD assessment process, across two localities in North Wales, highlighted more specific support was necessary. Suggestions ranged from the appointment of a key worker as a point of contact, the opportunity to speak to a counsellor and being introduced to other parents who have children with ASD (Griffiths, Walker-Jones, Fitzpatrick, Goodson, Pickering & Wimpory et al, 2013). These local findings closely map onto a breadth of qualitative research highlighting that parents/carers feel their needs are unmet in relation to post-diagnostic support (NICE CG170, 2013).

Effective post-diagnostic support may help address concerns reported by participants in the empirical paper, regarding having to disclose ASD to a peer and the fear of rejection that ensues. Such support may also increase parental understanding of ASD, addressing young people's concerns about being misunderstood by parents. In addition post-diagnostic support could help young people better understand themselves, by providing an explanation for the difficulties they face and facilitate acceptance of their diagnosis. Whilst participants in the empirical paper did not discuss issues relating to the impact of their diagnosis on their siblings, it would seem prudent for clinicians to include them in post-diagnostic support to increase understanding for the whole family.

Implications for clinical practice

Given the unique perspective Clinical Psychologists have in offering a collaborative, formulation-based approach, often in parallel to medical diagnosis, such post-diagnostic work would be an appropriate role for them to lead on within teams.

Both the empirical paper and literature review highlighted youth with ASD were able to discuss and reflect in detail on their internal experiences of anxiety. Therefore clinicians should ensure wherever possible the child's opinions and views are sought directly, particularly relating to anxiety following diagnosis. Hayne (2003) suggested clinicians should be able to offer helpful solutions whilst recognising the myriad of feelings youth with ASD may experience, including anxiety, when receiving a diagnosis. Explicitly asking questions such as "how does receiving this diagnosis make you feel?" or "do you worry how your friends may react to this?" is appropriate and important in assessing for anxiety post-diagnosis.

Diagnostic feedback sessions are often time-limited and restricted due to service constraints. Clinicians should be mindful of this, as the young person and their parents may be overwhelmed and misunderstand or forget key points discussed in such short sessions. Therefore using simplified language, concrete examples to support key points and focussing on individual's strengths, the attentive clinician may also want to ask certain questions to ensure information has been understood. Examples of

questions could be “Am I explaining things clearly enough for you?” or “Can I Just check that you are understanding what I am saying?” which will allow for a discussion where points can be clarified if needed.

It was clear that participants in the empirical paper had some awareness of their difference from peers, resulting in a fear of being judged or rejected. Clinicians could therefore support young people to accept this difference by considering the following suggestions. Firstly, it is important for clinicians to adopt a hopeful but realistic stance, describing the ways in which young people with ASD can live content and fulfilled lives. Secondly, offering young people specific structured post-diagnostic sessions may help develop a sense of acceptance relating to their diagnosis. Clinicians could consider including the following suggestions to structure their post-diagnostic support:

- Education about ASD tailored to intellectual ability.
- Normalisation of anxiety and the use of basic coping techniques such as deep breathing and distraction, a more specific form of which may be cognitive refocusing. An example of this would be to encourage the young person to focus intently on an object and describe it to themselves in great detail, thus re-focusing the mind away from the source of anxiety.
- Discussions about disclosure both to peers and others (including worries/concerns and ways to problem solve these). This should only be considered where consent to share information has been given and agreed.
- Planning for the future, considering any adaptations where necessary.

- The inclusion of parents and siblings in order to discuss impact on home life and help develop a family understanding of ASD and how this impacts on the young person's daily life.
- Signposting to third sector organisations such as the National Autistic Society so parents and young people can contact other families who have had similar experiences, where peer support can be sought.

Recommendations should be evidence-based so clinicians can be confident in the effectiveness of their approaches. The above implications and suggestions propose a number of interesting research questions that should be undertaken before firm conclusions can be made and are discussed under the proposed directions for future research section.

Intervention for Youth with ASD and Anxiety: Addressing Avoidance and Involving the Family

Research suggests that modified CBT is effective for youth with ASD and anxiety disorders (Reaven & Hepburn, 2003). However NICE guidance on how to care for youth with ASD (CG170, 2013) do not provide clinicians with specifics on how to modify CBT for youth with ASD and specific comorbid disorders such as OCD. Instead clinicians are given generic points to consider when using CBT with youth with ASD and are advised to consult non-ASD specific guidelines for the treatment of comorbid disorders. This means that clinicians have to consult two separate guidelines and make their own interpretations for what may work for a

young person with ASD. The likelihood for inconsistencies between clinicians here is high. It is therefore suggested that guidance on how to specifically modify CBT for youth with ASD and each specific comorbid disorder should be developed.

In addition, including the young person's family within CBT treatment for anxiety is supported by the literature review and empirical paper. The literature review recommended treatment for OCD in youth with ASD includes parents, to increase consistency of support between sessions and increase parental understanding of difficulties. This was of particular importance to participants in the empirical paper who expressed a need to feel understood by those supporting them.

When considering coping strategies used to manage anxiety, the findings of the empirical paper highlighted participants frequently used avoidance-based strategies. These included staying at home, withdrawing from friends and making excuses not to go into school. In addition there was a lack of awareness of the way in which these strategies may maintain anxiety in the long-term.

In contrast to avoidant-based coping, one participant reported being taught Mindfulness as a coping strategy and spoke very positively of it.

Simon "The other thing that I sometimes do is I'll make a point of getting a piece of chewing gum out and you know, well it's a CAMHS thing, do it very

slowly, very deliberately, very mindfully (…) [it's] very useful, it's probably the most useful thing they've kind of left me with".

It is unclear why only one participant was using mindfulness, given that three had received support for anxiety from CAMHS and two had received school-based counselling. Whilst it is noted that not all services are in a position to offer Mindfulness, it raises other possible explanations. There may be an issue of accessibility or clinicians may not be aware of the effectiveness of Mindfulness for youth with ASD. A lack of awareness could be explained by the limited research currently available regarding using mindfulness with individuals with ASD.

Implications for clinical practice

Clinicians should consider the important role of the parent(s)/carer(s) when developing interventions for youth with ASD and anxiety. In line with suggestions for the improvement to post-diagnostic support made above, interventions should support parents and young people to develop a shared understanding of the difficulties the young person faces. It is also important to provide education to parents about how reassurance, accommodation and inconsistency can obstruct treatment (Nadeau et al, 2014). Separate parent and child sessions should be offered as well as more collaborative joint sessions. Furthermore, emphasis should be placed on the inclusion of both parents as participants in the empirical paper reported a disparity between relationships with their mother's and

father's. Mother's were viewed as more understanding, supportive and available than father's. A suggestion here is that appointments should be flexible and offered outside of working hours, when both parents are often more available. Offering sessions during working and school hours could serve to reinforce the split between parents, as often only one attends. For the participants in the empirical paper this was often their mother. In addition, given that the judgements of others were a reported source of anxiety for participants, arranging appointments causing them to miss lessons every week may place extra emphasis on them being different to their peers. A solution here would be to offer evening appointments or ensure appointments are at the end of the working day. To enhance the collaborative approach, clinicians should ensure that following consent from the young person and their family, school staff are informed of treatment progress to improve generalisation of skills acquired through intervention.

Given the prevalence of avoidance-based coping, clinicians may wish to ensure that psychoeducation highlighting the way avoidance can maintain anxiety is incorporated throughout their interventions for anxiety. One commonly reported aspect of avoidance was that of social interactions with others. Therefore it would be appropriate to focus on developing social skills to provide support with this, to prevent avoidance leading to further social withdrawal and isolation. There are a number of social skills programmes that have been systematically reviewed, details of which are available in a meta-analysis by Bellini and Peters (2008).

Avoidance-based strategies could be replaced by more adaptive techniques, an example of which would be Mindfulness. Whilst the small sample size of the research paper limits generalisabilty, the overwhelmingly positive experience of one participant and the growing number of robust research, suggests mindfulness-based approaches may be useful for youth with ASD. Spek, van Ham and Nyklicek (2013) found modified Mindfulness was effective in treating symptoms of anxiety and depression in individuals with ASD.

Due to the nature of their diagnosis individuals with ASD often face life long difficulties e.g. with social interaction and rigidity of thinking. Therefore it can be hypothesised that an approach such as Mindfulness, with its focus on building resilience rather than "fixing" problems may be an appropriate intervention for those with ASD. Clinicians may therefore want to consider Mindfulness as a useful approach for individuals who have more chronic and severe difficulties, where a problem-solving approach such as CBT may be less effective.

From a service perspective researchers have highlighted the possibility that access to Mindfulness through current services is not equitable for youth with ASD compared to youth without ASD (Hastings, 2013). An audit of current practice in services within North Wales would be an appropriate starting point to explore this. If access to services was an issue, a potential solution would be to raise awareness and training within CAMHS teams,

highlighting the need to offer this approach to those with and without ASD, especially where anxiety is a concern.

In order to prevent youth having to wait until anxiety levels reach a level of severity meeting criteria for CAMHS, teachers and parents could be trained in Mindfulness. Research provides support for the positive effect training parents and teachers in mindfulness has on reducing challenging behaviour of youth with ASD and improving parental mental health and emotional wellbeing (Singh, Lancioni, Winton, Fisher, Wahler, McAleavey et al, 2006; Ferraiolo & Harris, 2013; Benn, Akiva, Arel & Roeser, 2012). However, more controlled research is needed into the effects Mindfulness training has on anxiety in youth with ASD, as this is limited at present.

A Proposed Direction for Future Research

Based on the findings of the empirical paper and the literature review there are a number of areas for future research.

It is important to establish how services currently approach the delivery of post-diagnostic support. Therefore a comprehensive audit focussing on how clinician's feedback diagnostic assessments, and the types of post-diagnostic support they offer, should be conducted. This will highlight any inconsistencies between services and clinicians and help to develop a

unified approach within North Wales. It would be useful to compare these local findings to wider findings within the UK in an effort to establish a consistent approach to post-diagnostic support.

The structure to post-diagnostic support previously suggested should help increase understanding of ASD and promote acceptance, preventing the development of difficulties such as anxiety. To evaluate this, clinicians may want to use standardised measures such as the Spence Anxiety Scale (SAS) for children or existing session outcome rating scales that focus on wellbeing. These have been developed and adapted for use with a range of intellectual disability and are currently being piloted within North Wales.

A useful way to establish the efficacy of a particular approach is to compared it to existing approaches. Therefore a relevant question is "Do different approaches to diagnostic support and feedback lead to differences in emotional wellbeing and acceptance in youth with ASD, following the receipt of their ASD diagnosis?" Researchers could adopt a controlled design where two groups are compared on measures of emotional wellbeing, following the delivery of either the above structured format or the standard approach currently used within services (highlighted through the audit recommended above). Satisfaction and mood questionnaires such as the SAS, or a more comprehensive measure such as the Beck Youth Inventory (BYI), could be compared between groups at specific time intervals (pre and post-delivery) to measure outcome. Qualitative

information about the experience of different approaches could also be collected.

There is limited qualitative research focussing specifically on the experiences of children and adolescents with ASD. The findings of the empirical paper could be extended to explore the experiences of youth with ASD and specific anxiety disorders such OCD and Social Anxiety, especially given the high prevalence rates of these two disorders within this population (Rudy, Lewin & Storch, 2013). Researchers may also wish to consider selecting participants that have all received a particular form of therapy, to investigate the effectiveness of particular components. There is a large amount of questionnaire-based prevalence research showing those with ASD have greater levels of anxiety disorders compared to typically developing individuals. Whilst this is useful, such research does not allow for subtle individual characteristics to be captured as they often use standardised questionnaires, based on strict diagnostic criteria allowing for a restricted response, usually a tick in a box. How a young person with ASD experiences particular anxiety disorders, how they make them feel and think is under researched, particularly from a qualitative perspective. By carrying out such research, theories into the interplay between anxiety and ASD in youth can continue to be developed.

To improve current guidelines, more specific advice for adapting CBT for youth with ASD and anxiety is needed, in particular separating guidance according to specific anxiety disorder. This is supported by

recommendations from research reviewing modifications to CBT for anxiety disorders in this population (Moree & Davis, 2010). Whilst there are commonalities between the treatments for each anxiety disorder, there are likely to be unique aspects that are disorder-specific, thus prompting subtle differences in emphasis with different modifications to make (Moree & Davis, 2010). At present this information is not readily available to clinicians. A way forward here would be to conduct systematic literature reviews of the evidence base for ASD-specific treatment of particular anxiety disorders. At present the majority of research regarding effective treatment for specific anxiety disorders in youth with ASD exists at the single case level. In order for effective approaches to be included within NICE guidelines more controlled group designs should be adopted to better establish efficacy.

Research on Mindfulness for youth with ASD suggested this approach can be modified for this population, taking into account different communication styles and intellectual functioning (Singh et al 2006). However, the majority of controlled trials appear to focus on parent/teacher training and on reducing challenging behaviour and aggression, rather than on training youth themselves or focussing on mood based problems. Whilst research with adults with ASD and anxiety shows mindfulness to have a positive effect on anxiety, future research should begin to establish it's impact in youth with ASD, in order for it be more routinely and equitably offered to this population.

Personal reflections

Throughout my time as a Trainee Clinical Psychologist I have had the opportunity to develop an interest in working with individuals on the Autism Spectrum, more specifically how services are configured to support individuals, some of whom also have complex mental health difficulties. My motivation for this comes from seeing how the son of a close family friend with ASD struggled to get support from local services. Over the years I have spoken many times with him and his parents, who both described that being passed from pillar-to-post between services, only to be told no specific service (health or education) was available for their son, was both deeply upsetting and frustrating. Eventually a number of services became available and their son flourished and both he and his parents described having a completely different life. This highlighted to me that with the right type of support and the motivation and dedication from supportive parents, children with ASD could lead happy and contented lives and overcome the challenges that are inherent with their lifelong diagnosis. With this in mind I felt I wanted to learn more about the experiences of young people with ASD and how they experience support services, in particular how services could be developed to best meet the needs of this population.

Throughout this project I was encouraged to keep a record of my thoughts and reflections at each stage. After looking back at these a number of significant ones stood out. To begin with, the initial stage of applying for

ethical approval was something that I noticed left me with a mixture of feelings. These ranged from frustration to relief, and an unlikely appreciation for a process that is both necessary and painstaking at the same time. Despite the frustration at having to fill in a very comprehensive form with lots of repetition, I feel that the process encouraged me to consider the finer points, which I can now see, are crucial when conducting research. An example of this is how to best disseminate the results and feedback the findings, something that I will undoubtedly find useful throughout my career as a Clinical Psychologist.

I found interviewing my participants both a privilege and a challenge. The fact that I was able to sit and listen to young people share their difficulties with me left me feeling humbled. However, at times I felt torn between the role of a clinician with a tendency to support, comfort and problem solve, and that of a researcher whose role is primarily to listen from a more neutral perspective. Whilst I realised that I was able to be a compassionate researcher it left me with an interesting question. Is it more difficult for a person who uses IPA to bridge the hermeneutic gap (thus see the point of view of the individual) with someone who they don't understand or even like? Whilst I can honestly say that I never felt that I disliked any of my participants, there were times when I was mindful of some frustration, especially when I was finding it difficult to keep one participant on track. I noticed this frustration when carrying out the analysis and working through the transcript of this particular participant for the first few times. I remember feeling annoyed when the participant glossed over a question

that I felt was important and gave a long answer to something I expected would be brief. When I became aware of these feelings I stopped the analysis, took a break and returned after a few minutes, which allowed me to refocus.

A second reflection during the interview stage was my conducting the majority of the interviews in the participants' own home. I remember feeling significantly more confident and comfortable when conducting one interview in a clinic room where I was on placement, when compared to being in the participants' own home. I think this was because part of me felt as if I was invading their privacy and interrupting their daily routine. It must be noted that I was made to feel welcome in all the homes that I attended, and I noticed that the more interviews I did the more comfortable I became and found that it was easier to develop rapport with the young person.

I had never done IPA before but wanted to broaden my research experience and it was partly for this reason that I committed to using the methodology. The way in which IPA relies on the interpretations of the researcher and acknowledges that the experiences of the researcher influence the results, left me questioning whether my interpretations at times were in grounded in the words of the participant or overly influenced by my expectations. Whilst this was addressed through the triangulation process with my supervisor, I was still left feeling that this particular approach lacks the scientific rigour that comes with quantitative

approaches and at times felt myself wishing I had done a quantitative study. However the more I developed the narrative the more I was glad that I had persevered with the approach, as this client group is underrepresented in qualitative research. From conducting extensive literature searches in this topic, both prior to starting the project and during the write up, a concern of mine is that there is an overreliance on parental/carer report with an assumption that youth with ASD don't have the ability to report on their own feelings and thoughts. For this reason I feel privileged to be able to contribute in some way to this area of research.

I became a father during the writing up process of this project, which whilst being exciting brought with it its own challenges. Balancing workloads and sticking to personal deadlines became very important in order for me to stay focussed. This allowed me to further realise my abilities to manage both personal and professional responsibilities, whilst turning to family members for support when needed.

To conclude, I have found the process of planning, executing and writing up my research project to be at times challenging both intellectually and emotionally. It is something that I am proud to have achieved, however when I think back across the 18 months it has taken me to complete this, I can remember feeling a range of emotions including excitement, apprehension, frustration and self-doubt. Self-doubt is the most difficult emotion that I have faced throughout the project as I entered into this with very little research experience. One thing that I feel has helped me manage

this is talking with my colleagues and fellow trainees. From conversations with them I have come to realise that such feelings are commonplace on the journey to becoming a qualified Clinical Psychologist.

References

Bellini, S., & Peters, J. K. (2008). Social skills training for youth with autism spectrum disorders. *Child and adolescent psychiatric clinics of North America*, *17*(4), 857-873.

Benn, R., Akiva, T., Arel, S., & Roeser, R. W. (2012). Mindfulness Training Effects for Parents and Educators of Children With Special Needs. *Developmental Psychology 48*(5), 1476-87.

Ferraioli, S. J., & Harris, S. L. (2013). Comparative effects of mindfulness and skills-based parent training programs for parents of children with autism: Feasibility and preliminary outcome data. *Mindfulness*, *4*(2), 89-101.

Griffiths, G. M., Walker-Jones, E., Fitzpatrick, H., Goodson, L., Pickering, N., Wimpory, D., et al. (2013). Receiving an assessment and a potential diagnosis on the Autism Spectrum. *Good Autism Practice, 14(2)*, 59-68.

Hastings, R. P. (2013). Mindfulness in the field of intellectual disability and autism: A bandwagon, or a considered development?. ProfHasting's Blog (web log). Retrieved May, 2014, from http://profhastings.blogspot.co.uk/2013_08_01_archive.html.

Moree, B. N., & Davis, T. E. (2010). Cognitive-behavioral therapy for anxiety in children diagnosed with autism spectrum disorders: Modification trends.

Research in Autism Spectrum Disorders. 4, 346–354.

National Institute for Health and Care Excellence (2013). Autism in children and young people. (CG128). London: National Institute for Health and Care Excellence

National Institute for Health and Care Excellence (2013). The management and support of children and young people on the Autism Spectrum. (CG170). London: National Institute for Health and Care Excellence

Reaven, J., & Hepburn, S. (2003). Cognitive-behavioural treatment of obsessive-compulsive disorder in a child with Asperger syndrome: a case report. *Autism, 7(2),* 145-64.

Rudy, B. M., Lewin, A B., & Storch, E. A. (2013). Managing anxiety comorbidity in youth with autism spectrum disorders. *Neuropsychiatry, 3(4),* 411-421.

Singh, N. N., Lancioni, G. E., Winton, A. S., Fisher, B. C., Wahler, R. G., Mcaleavey, K., et al. (2006). Mindful parenting decreases aggression, noncompliance, and self-injury in children with autism. *Journal of Emotional and Behavioral Disorders*, *14*(3), 169-177.

Spek, A. A., van Ham, N. C., & Nyklíček, I. (2013). Mindfulness-based therapy in adults with an autism spectrum disorder: A randomized controlled trial. *Research in developmental disabilities*, *34*(1), 246-253.

SECTION 5: Ethics Appendix

Ethical Application to School of Psychology, Bangor University

Application for Ethical Approval

Project Title: The experience of Anxiety for young people with ASD

Principal investigator: Kornecki, Pasquale

Other researchers: Brennan,Angela, Griffith,Gemma

Pre-screen Questions

Type of Project
D.Clin.Psy

What is the broad area of research
Clinical/Health

Funding body

Type of application (check all that apply)
Project requiring scrutiny from an outside body which has its own ethical forms and review procedures

Proposed methodology (check all that apply)
Questionnaires and Interviews

Do you plan to include any of the following groups in your study?
Children

If your research requires any of the following facilities MRI, TMS/ tCS, Neurology Panel, has the protocol been reviewed by the appropriate expert/safety panel?
Not applicable (the research does not require special safety panel approval)

Connection to Psychology, (i.e. why Psychology should sponsor the question)
Investigator is a student in Psychology (including the North Wales Clinical Psychology Programme)

Does the research involve NHS patients? (NB: If you are conducting research that requires NHS ethics approval make sure to consult the Psychology Guidelines as you may not need to complete all sections of the Psychology online application)
Yes, NHS IRAS application attached.

Has this proposal been reviewed by another Bangor University Ethics committee?
No

Part 1: Ethical Considerations

Will you describe the main experimental procedures to participants in advance, so that they are informed about what to expect?
Yes
Further details: see supporting documentation

Will you tell participants that their participation is voluntary?
Yes
Further details: see supporting documentation

Will you obtain written consent for participation?
Yes
Further details: see supporting documentation

If the research is observational, will you ask participants for their consent to being observed?
N/A

Will you tell participants that they may withdraw from the research at any time and for any reason?
Yes
Further details: see supporting documentation

With questionnaires, will you give participants the option of omitting questions they do not want to answer?
Yes
Further details: see supporting documentation

Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?
Yes
Further details: see supporting documentation

Will you debrief participants at the end of their participation (i.e. give them a brief explanation of the study)?
N/A

Will your project involve deliberately misleading participants in any way?
No

Is there any realistic risk of any participants experiencing either physical or psychological distress or discomfort? If *Yes* , give details and state what you will tell them to do should they experience any problems (e.g., who they can contact for help)
Yes
Further details: Given the nature of the research there is potential for some people to find some of the questions sensitive. However previous research involving direct interviews with young people and adults with high functioning autism or Asperger syndrome suggest that participants do not typically become distressed. Particular attention will be paid to this during the process with regular breaks and time given to the young person. If requested by the young person, a parent can be present during the interview. In addition it will be explicitly mentioned that the child can choose to stop the interview for any reason by asking the interviewer to do so, after which reassurance and support will be provided to the young person, with a follow-up telephone call delivered in the event of an interview termination due to distress. This is likely to occur following discussion with the supervisory team up to 48 hours after the event. If during the interview the young person gives information indicating that they or someone else is at risk of significant harm, BCUHB and All Wales Policy for safeguarding children will be followed. If there are any concerns in relation to risk of harm, supervision from the clinical supervisor will be sought. If they are in school and

there are any concerns about the young person's well being, the researcher can liaise with the designated member of the teaching staff who are level two trained in recognising and supporting children who experience mental health difficulties. These particular members of staff have procedures to follow in the event of a child requiring such support, which can involve contacting CAMHS. In the unlikely event of any child becoming distressed as a result of the interview process the lead researcher can liaise with a member of the supervision team. It is also important to spend some time following the interview to find out how the young person feels and if there are any issues that need addressing. This will be done verbally immediately after the interview, or if this is not possible a follow up telephone conversation. If the child becomes distressed during an interview that takes place,parents will be informed.

Is there any realistic risk of any participants experiencing discomfort or risk to health, subsequent illness or injury that might require medical or psychological treatment as a result of the procedures?
No

Does your project involve work with animals? If *Yes* please complete Part 2: B
No

Does your project involve payment to participants that differs from the normal rates? Is there significant concern that the level of payment you offer for this study will unduly influence participants to agree to procedures they may otherwise find unacceptable? If *Yes* please complete Part 2: B and explain in point 5 of the full protocol
No

If your study involves children under 18 years of age have you made adequate provision for child protection issues in your protocol?
Yes
Further details: see supporting documentation

If your study involves people with learning difficulties have you made adequate provision to manage distress?
N/A

If your study involves participants covered by the Mental Capacity Act (i.e. adults over 16 years of age who lack the mental capacity to make specific decisions for themselves) do you have appropriate consent procedures in place? NB Some research involving participants who lack capacity will require review by an NHS REC. If you are unsure about whether this applies to your study, please contact the Ethics Administrator in the first instance
N/A

If your study involves patients have you made adequate provision to manage distress?
Yes
Further details: see supporting documentation

Does your study involve people in custody?
No

If your study involves participants recruited from one of the Neurology Patient Panels or the Psychiatry Patient Panel then has the protocol been reviewed by the appropriate expert/safety panel?
N/A

If your study includes physically vulnerable adults have you ensured that there will be a person trained in CPR and seizure management at hand at all times during testing?
N/A

Is there significant potential risk to investigator(s) of allegations being made against the investigator(s). (e.g., through work with vulnerable populations or context of research)?
Yes
Further details: Local lone working policy (BCUHB policy) will be implemented when carrying interviews with the children. Initial conversations via telephone will be had with young people and their parents interested in taking part in the project about how and where they would like to be interviewed. Wherever possible the lead researcher will endeavour to fit in with the needs and requirements of the young person. This will include being flexible around interview location with options including the individual's home, school, local GP surgery or local CAMHS clinic. Opportunity for parents to be present during these will be given to each participant with the expectation that parents will be at the famly home when interviews occur there. Supervision will be regularly used in order to be mindful of any issues relating to the wellbeing of the researcher given the nature of the topic. There are also support networks that can be accessed through NWCPP. At the beginning of each interview information will be provided regarding BCUHB policy on confidentiality and its limitations regarding concerns over harm to self or others.

Is there significant potential risk to the institution in any way? (e.g., controversiality or potential for misuse of research findings.)
No

Part 3: Risk Assessment

Is there significant potential risk to participants of adverse effects?
No

Is there significant potential risk to participants of distress?
Yes
Further details: Given the nature of the research there is potential for some people to find some of the interview questions sensitive. However previous research involving direct interviews with young people and adults with high functioning autism or Asperger syndrome suggest that participants do not typically become distressed. Particular attention will be paid to this during the process with regular breaks and time given to the young person. If requested by the young person, a parent can be present during the interview. In addition it will be explicitly mentioned that the child can choose to stop the interview for any reason by asking the interviewer to do so, after which reassurance and support will be provided to the young person, with a follow-up telephone call delivered in the event of an interview termination due to distress. This is likely to occur following discussion with the supervisory team up to 48 hours after the event. If during the interview the young person gives information indicating that they or someone else is at risk of significant harm, BCUHB and All Wales Policy for safeguarding children will be followed. If there are any concerns in relation to risk of harm, supervision from the clinical supervisor will be sought. If they are in school and there are any concerns about the young person's well being, the researcher can liaise with the designated member of the teaching staff who are level two trained in recognising and supporting children who experience mental health difficulties. These particular members of staff have procedures to follow in the event of a child requiring such support, which can involve contacting CAMHS. In the unlikely event of any child becoming distressed as a result of the interview process the lead researcher can liaise with a member of the supervision team. It is also important to spend some time following the interview to find out how the young person feels and if there are any issues that need addressing. This will be done verbally immediately after the interview, or if this is not possible a follow up telephone conversation. If the child becomes distressed during an interview that takes place,parents will be informed.

Is there significant potential risk to participants for persisting or subsequent illness or injury that might require medical or psychological treatment?
No

Is there significant potential risk to investigator(s) of violence or other harm to the investigator(s) (e.g., through work with particular populations or through context of research)?
Yes
Further details: Due to the nature of the research and the client group there is a minimal possibility that individuals may become distressed as a result of being interviewed. This is not expected to be the case, however if this was to happen the interview wold be stopped, the participants parents would be informed and supervision would be sought. all attempts to assess such risk would be taken prior to the interview through conversation with young person and their parents.

Is there significant potential risk to other members of staff or students at the institution? (e.g., reception or other staff required to deal with violent or vulnerable populations.)
No

Does the research involve the investigator(s) working under any of the following conditions: alone; away from the School; after-hours; or on weekends?
Yes
Further details: Local BCUHB lone working policy will be implemented when working in the participants home; which will include informing colleagues of where the researcher is going and when they are likely to return. Visitis to schools and GP clinics will take place before interviews occur in order to familiarise with the environment. staff in these settings will be made aware of when the interviews will be taking place and their polices about such working will be consulted and implemented.

Does the experimental procedure involve touching participants?
No

Does the research involve disabled participants or children visiting the School?
No

Part 2: A

The potential value of addressing this issue

Hypotheses

Participants recruitment. Please attach consent and debrief forms with supporitng documents

Research methodology

Estimated start date and duration of the study.

For studies recruiting via SONA or advertising for participants in any way please provide a summary of how participants will be informed about the study in the advertisement. N.B. This should be a brief factual description of the study and what participants will be required to do.

Part 2: B

Brief background to the study

Further details: Very little is known about how anxiety is experienced by young people who have a diagnosis of ASD in relation to how anxiety influences their thinking, feelings and physical experiences. Therefore this is a qualitative study to gain an understanding of the experience of anxiety in young people diagnosed with Autistic Spectrum Disorder (ASD)through the use of semi structured interviews to allow individuals to talk about their experiences. 1 in 150 children and young people typically have severe deficits in social communication and restricted interests (Centres for Disease Control, 2007) with anxiety related symptoms being amongst the most common comorbid difficulty found in children and adolescents with ASD (Ghazzihudin, 2002). Given this relatively high prevalance rate of ASD and anxiety related difficulties in children it seems appropriate to gain a greater understanding of what this means for those young people living with these difficulties. This can include the direct lived experience of the individual but also focussing on their experiences of treatment/support for such anxiety related difficulties. This in turn may inform how best to approach such difficulties with individuals to tailor them effectively, (Humphries Lewis, 2008). Research in this field has typically focussed on the accounts of parents or care-givers of the young person or used standardised measures such as questionnaires to elicit information from the young person themselves. The use of such standardised measures may not capture the individual nuances of living with such difficulties, therefore a less restrictive qualitative approach may be a more appropriate method of analysis to gain a deeper understanding of the young persons experiences. There is qualitative research looking into the experiences of children with ASD, in particular looking at social interaction and friendships (Daniel Billingsley, 2010). In addition more recent studies have looked at parental/caregiver understandings of the relationship between their child's anxiety and ASD (Ozsivadjian, Knott Magiati, 2012), however qualitative research focusing on the interaction between ASD and anxiety in young people does not seem to have been conducted with a specific focus on the young people themselves.

The hypotheses

Further details: From a theoretical perspective, the views of young people themselves may lead to a quite different understanding of anxiety within ASD and even different ways of assessing/measuring and understanding the severity of anxiety "symptoms". Given the importance for including service users in the development of services and treatment interventions it is also important to gain an understanding of such subjective experiences in order to shape future services effectively. It is for these reasons that the current project has been developed.

Participants: recruitment methods, age, gender, exclusion/inclusion criteria

Further details: Once ethical approval has been gained recruitment will begin immediately. This is expected to be April 2013. Stage 1: Initial meetings will be held with local CAMHS teams, Educational Psychologist working within North Wales and local ASD support groups (e.g.National Autistic Society (NAS) and Autism Initiatives) and voluntary organisations (Jigsaw, Createasmile) across North Wales. Where cases have been closed to professionals working with them a specific cover letter will be sent to the family signed by the professional asking if they would like to take part in the study (see attached document.) The purpose of these meetings is to promote the research and allow professionals to consider whether they are aware of any potential participants. Professionals will be given clear inclusion/exclusion criteria and asked to identify potential suitable participants from their previous or current case loads. The lead researcher will attend support group meetings and hand out information packs, opt in forms and a covering letter to those that are interested in taking part in the study. At this stage the lead researcher will discuss the exclusion and inclusion criteria with the parents in attendance. If there are any concerns or queries at this stage regarding exclusion criteria then participants will not be included in the study at this time. According to the National Public Health Service for Wales (2009) there are approximately 162,000 children and young people between the ages of 5-24 years living in North Wales. NAS suggest that the best estimate for ASD prevalence in children is 1 in 100. Therefore based on the above figures one can expect to find approximately 1,620 children with a diagnosis of ASD in North Wales. It is thought that 15 participants would be sufficient. This number is greater than normally expected for an interpretative Phenomenological Analysis (IPA), however due to the fact that sometimes children with ASD may find it difficult to participate in long in depth interviews and for various reasons may struggle to answer questions in great detail, recruiting a larger number may ensure that the quality and depth of data is high. Stage 2: The professionals are then invited to contact the young person

and their family and discuss the nature of the study by inviting them either to their local clinic for a face-to-face discussion, contacting them via telephone or visiting them at their home. The purpose of this is to see if they want to opt in to the study which means that they agree to the lead researcher sending them more detailed information about the study through the post (see attached documents). Within this information will be a consent form and a stamped addressed envelope. Stage 3: Upon receipt of signed consent forms the lead researcher will telephone the family to arrange to meet. During this phone call it is hoped that the lead researcher will speak to both the parents and the young person themselves. In addition further question about inclusion and exclusion criteria will be discussed with parents and/or the young person themselves. Stage 4: A letter will be sent to the young person and their family to confirm the date of the interview. With this an anxiety experience diary (see attached forms) will be enclosed with instructions on how to complete this. This diary sheet is for the participant, (if agreeable) to keep a record of experiences of anxiety over a period of one week using a specially designed diary format (see attached documents). These will be collected on the day of the interview. Stage 5: Individual meetings will be arranged with the young person (and parents if the young person wants them there) at a site of their choosing (home, school, CAMHS clinic or GP surgery)approximately one week after receiving the anxiety diary. Prior to the interview starting the Spence Anxiety questionnaire will be completed and the semi structured interview will be carried out with the young person, (see attached documentation). It is hoped that a semi–structured interview format will enable some comparability and containment for the participant, whilst enabling scope to explore further any areas which may be of importance or interest. The flexibility of the interview format will also help to build rapport with the participants, which is important when exploring a sensitive area such as this. Expected time frame to begin interviews is June 2013. The lead researcher will go over the areas on the participant information sheet which concern consent, agreement to be recorded and the participants right to withdraw from the interview at any time. At the beginning of the interview the lead researcher will also explain that everything discussed is confidential, unless they disclose information which the lead researcher feels poses a risk of harm to themselves or others. If this situation occurs the lead researcher will discuss their concerns with the participant, before passing the information on to the participants parents and provide information to them about services that may be able to offer support. Participants will be given the opportunity to ask any questions and then a Spence anxiety questionnaire will be delivered to provide some contextual information about the young persons current level of anxiety. (This questionnaire will be scored within 48 hours of completion and the results discussed with the supervisory team. If a concern is raised at the time of scoring the questionnaire then the parents of the young person will be contacted where there will be a potential to give advice about where to find the most appropriate support.) The lead researcher will test the digital voice recorder to ensure it is working correctly and commence the interview. Stage 6: Analysis of both interview transcripts and experience diaries will occur in parallel with stage 5. As soon as interviews are completed transcripts will start to be analysed. The same applies to the completion and submission of experience diaries. Interviews will analysed using Interpretive Phenomenological Analysis (IPA). Following analysis feedback will be provided either through the post in the form of a written report or by telephone contact with the family and the young person. Final analysis is hoped to be completed by January 2014 with a draft report completed by March 2014. Feedback to Parents and Young people will be in April 2014 with a final submission date of the project in June 2014. Inclusion criteria: Inclusion criteria will be young people with a diagnosis of ASD who have been identified as experiencing anxiety related difficulties where intervention for anxiety related difficulties has been provided. It is likely that some cases will be currently receiving input from CAMHS. In some instances cases may be closed to CAMHS but open for medication review or receiving active intervention from other services such as Educational Psychology. Cases accessed through Educational Psychology and local support groups such as NAS and autism initiatives may not be open to CAMHS but still approached through the recruitment process. Young people will be of secondary school age ranging from 11 years to 18 years. Exclusion Criteria: The presence of an identified learning disability will be an exclusion criterion. A further exclusion criterion will be the presence of an additional mental health problem that may affect the young person's ability to participate in the interview process (e.g., active psychosis).

Research design

Further details: This is a qualitative study using semi structured interviews and experience diaries analysed using Interpretive Phenomenological Analysis (IPA)

Procedures employed

Further details: Once ethical approval has been gained recruitment will begin immediately. This is expected to be April 2013. Stage 1: Initial meetings will be held with local CAMHS teams, Educational Psychologist working within North Wales and local ASD support groups (e.g.National Autistic Society (NAS) and Autism Initiatives) and voluntary organisations (Jigsaw, Createasmile) across North Wales. Where cases have been closed to professionals working with them a specific cover letter will be sent to the family signed by the professional asking if they would like to take part in the study (see attached document.) The purpose of these meetings is to promote the research and allow professionals to consider whether they are aware of any potential participants. Professionals will be given clear inclusion/exclusion criteria and asked to identify potential suitable participants from their previous or current case loads. The lead researcher will attend support group meetings and hand out information packs, opt in forms and a covering letter to those that are interested in taking part in the study. At this stage the lead researcher will discuss the exclusion and inclusion criteria with the parents in attendance. If there are any concerns or queries at this stage regarding exclusion criteria then participants will not be included in the study at this time. According to the National Public Health Service for Wales (2009) there are approximately 162,000 children and young people between the ages of 5-24 years living in North Wales. NAS suggest that the best estimate for ASD prevalence in children is 1 in 100. Therefore based on the above figures one can expect to find approximately 1,620 children with a diagnosis of ASD in North Wales. It is thought that 15 participants would be sufficient. This number is greater than normally expected for an interpretative Phenomenological Analysis (IPA), however due to the fact that sometimes children with ASD may find it difficult to participate in long in depth interviews and for various reasons may struggle to answer questions in great detail, recruiting a larger number may ensure that the quality and depth of data is high. Stage 2: The professionals are then invited to contact the young person and their family and discuss the nature of the study by inviting them either to their local clinic for a face-to-face discussion, contacting them via telephone or visiting them at their home. The purpose of this is to see if they want to opt in to the study which means that they agree to the lead researcher sending them more detailed information about the study through the post (see attached documents). Within this information will be a consent form and a stamped addressed envelope. Stage 3: Upon receipt of signed consent forms the lead researcher will telephone the family to arrange to meet. During this phone call it is hoped that the lead researcher will speak to both the parents and the young person themselves. In addition further question about inclusion and exclusion criteria will be discussed with parents and/or the young person themselves. Stage 4: A letter will be sent to the young person and their family to confirm the date of the interview. With this an anxiety experience diary (see attached forms) will be enclosed with instructions on how to complete this. This diary sheet is for the participant, (if agreeable) to keep a record of experiences of anxiety over a period of one week using a specially designed diary format (see attached documents). These will be collected on the day of the interview. Stage 5: Individual meetings will be arranged with the young person (and parents if the young person wants them there) at a site of their choosing (home, school, CAMHS clinic or GP surgery)approximately one week after receiving the anxiety diary. Prior to the interview starting the Spence Anxiety questionnaire will be completed and the semi structured interview will be carried out with the young person, (see attached documentation). It is hoped that a semi–structured interview format will enable some comparability and containment for the participant, whilst enabling scope to explore further any areas which may be of importance or interest. The flexibility of the interview format will also help to build rapport with the participants, which is important when exploring a sensitive area such as this. Expected time frame to begin interviews is June 2013. The lead researcher will go over the areas on the participant information sheet which concern consent, agreement to be recorded and the participants right to withdraw from the interview at any time. At the beginning of the interview the lead researcher will also explain that everything discussed is confidential, unless they disclose information which the lead researcher feels poses a risk of harm to themselves or others. If this situation occurs the lead researcher will discuss their concerns with the participant, before passing the information on to the participants parents and provide information to them about services that may be able to offer support. Participants will be given the opportunity to ask any questions and then a Spence anxiety questionnaire will be delivered to provide some contextual information about the young persons current level of anxiety. (This questionnaire will be scored within 48 hours of completion and the results discussed with the supervisory team. If a concern is raised at the time of scoring the questionnaire then the parents of the young person will be contacted where there will be a potential to give advice about where to find the most appropriate support.) The lead researcher will test the digital voice recorder to ensure it is working correctly and commence the interview. Stage 6: Analysis of both interview transcripts and experience diaries will occur in parallel with stage 5. As soon as interviews are completed transcripts will start to be analysed. The same applies to the completion and submission of experience diaries. Interviews will analysed using Interpretive Phenomenological Analysis (IPA). Following analysis feedback

will be provided either through the post in the form of a written report or by telephone contact with the family and the young person. Final analysis is hoped to be completed by January 2014 with a draft report completed by March 2014. Feedback to Parents and Young people will be in April 2014 with a final submission date of the project in June 2014.

Measures employed
Further details: Spence Anxiety Questionnaire

Qualifications of the investigators to use the measures (Where working with children or vulnerable adults, please include information on investigators' CRB disclosures here.)
Further details: Lead researcher is a trainee clinical psychologist employed by BCUHB and NWCPP, therefore has full CRB clearance. Clinical supervision will be provided by an experienced clinical psychologist (Angela Brennan) and research supervision will be provided by an experienced researcher employed by the school of psychology bangor university, (Gemma Griffith).

Venue for investigation
Further details: Interviews will take place in local CAMHS clinics across North Wales, Participant homes, local schools and GP surgeries. This will be decided at the request of the young person and their families

Estimated start date and duration of the study (N.B. If you know that the research is likely to continue for more than three years, please indicate this here).
Further details: Research is likely to commence in June 2013 and will run for approximately 12 months.

Data analysis
Further details: Data will be analysed using IPA and supervised by Dr Gemma Griffith

Potential offence/distress to participants
Further details: Given the nature of the research there is potential for some people to find some of the questions sensitive. However previous research involving direct interviews with young people and adults with high functioning autism or Asperger syndrome suggest that participants do not typically become distressed. Particular attention will be paid to this during the process with regular breaks and time given to the young person. If requested by the young person, a parent can be present during the interview. In addition it will be explicitly mentioned that the child can choose to stop the interview for any reason by asking the interviewer to do so, after which reassurance and support will be provided to the young person, with a follow-up telephone call delivered in the event of an interview termination due to distress. This is likely to occur following discussion with the supervisory team up to 48 hours after the event. If during the interview the young person gives information indicating that they or someone else is at risk of significant harm, BCUHB and All Wales Policy for safeguarding children will be followed. If there are any concerns in relation to risk of harm, supervision from the clinical supervisor will be sought. If they are in school and there are any concerns about the young person's well being, the researcher can liaise with the designated member of the teaching staff who are level two trained in recognising and supporting children who experience mental health difficulties. These particular members of staff have procedures to follow in the event of a child requiring such support, which can involve contacting CAMHS. In the unlikely event of any child becoming distressed as a result of the interview process the lead researcher can liaise with a member of the supervision team. It is also important to spend some time following the interview to find out how the young person feels and if there are any issues that need addressing. This will be done verbally immediately after the interview, or if this is not possible a follow up telephone conversation. If the child becomes distressed during an interview that takes place,parents will be informed.

Procedures to ensure confidentiality and data protection
Further details: Use of personal information such as addresses and emails: This information will not be known to the researchers until contacted by participants or the participants have returned the consent form with the contact details they would like the researcher to use (e.g. phone number or email). The contact details will not be shared with anyone outside the named research team. Publication of direct quotations from respondents: All direct quotes from participants, when written up for publication or for internal reports will

be made anonymous, either with a participant number or a pseudonym. Any potentially identifying information (e.g. names of professionals or places) will also be removed. Use of audio/visual recording devices: A digital recorder will be used to record the interviews. Written consent will be sought (see consent form) and the participant will again be asked for verbal permission to record the interview just before it commences. After the interview has finished, it will be securely downloaded onto the researchers University computer, the file given a number to ensure anonymity, and the interview will be deleted from the digital recorder once the download is complete to enhance security. Storage of personal data on any of the following: Manual files (includes paper or film): The consent forms will have the contact information of the participants on them, and will be stored at Bangor University in a locked filing cabinet. Each participant will be given an identification number that will be written on the consent form. Thereafter all digital data will refer to this identification number, to keep the identity of participants anonymous. The only way of matching a digital file to a participant's name will be by referring to the manual files. University computers: The university computer is password protected. The digital files from the interviews will be stored on a university computer, each file will be password protected. Each interview will be given a number which can be linked to participants only via the consent forms (which will be in a locked cabinet within Bangor University). Additionally, the transcripts of the interviews will be stored on a university computer, the files will be stored using the identification number. In addition data is likely to be stored on a university selected secure USB pen drive. This is password encrypted and data files will be given a number to ensure anonymity. The BCUHB policy on confidentiality will be adhered to at all times. Participants will not be identifiable either from computer records or written reports/publications. All direct quotes from participants, when written up for publication or reports will be made anonymous, either with assigned numbers or a pseudonym. Any potentially identifying information (e.g. names of professionals or places) will also be removed.

How consent is to be obtained (see BPS Guidelines and ensure consent forms are expressed bilingually where appropriate. The University has its own Welsh translations facilities on extension 2036)
Further details: All written information will be provided bi-lingually but unfortunately the resources are not available to be able to offer bilingual interviews. The interview schedule has been devised under the supervision of Dr Gemma Griffith who has lots of experience at conducting and using IPA to analyse such interviews with adults and young people with ASD. It is therefore thought the interview questions/protocol will not only be appropriately selected but suit the methodology for analysis. During the recruitment stage a telephone conversation will be made by the lead researcher to the family to arrange the interview. It is thought that at this stage attempts will be made to speak to the young person themselves and allow them to ask questions. Given one exclusion criteria is the presence of an identified Learning Disability it is expected that the young person will have a working knowledge and understanding of language. However discussion with the parents will provide further information regarding this. The use of pictures and simple text will be chosen in order to ensure clarity. Welsh translations of all information sheets will be given to participants. The information sheets will be translated pending approval for the ethics board. Initial contact will be made via a professional that has worked with the individual. They will be asked to opt in so that the lead researcher can send out information and further consent forms in the post to them. Once people have opted in information packs will be sent including a consent form for both children and parents to sign. Once this is returned via stamped addressed envelope the researchers are able to make contact with the family. Upon meeting with family the aims and purpose of the study will be reiterated in order to reaffirm consent at the stage. Information sent to the families will be clearly written and concise ensuring that technical jargon is kept to a minimum. Enclosed will be an outline of the aims of the research with a picture of the lead researcher in order to allow the potential participants to familiarise themselves with the lead researcher prior to meeting. This will reduce further anxiety that may arise when meeting someone new for the first time. (Please see attached documents)A cover letter confirming the date and time of the interview will be sent along with a template anxiety experience diary sheet with instructions on how to complete this. (see attached documentation)

Information for participants (provide actual consent forms and information sheets) including if appropriate, the summary of the study that will appear on SONA to inform participants about the study. N.B. This should be a brief factual description of the study and what participants will be required to do.
Further details: see attached documentation

Approval of relevant professionals (e.g., GPs, Consultants, Teachers, parents etc.)

Further details: Email contact will be made to all recruitment agencies (CAMHS clinicians, Educational Psychologists, Autism Charities and local support groups.

Payment to: participants, investigators, departments/institutions
Further details: For participation a £10 voucher or certificate (identified by the individual in the initial consent form) will be provided for each young person; this will be covered within the NWCPP budget. Whilst there does not appear to be any published guidelines specifically focussing on the provision of incentives/rewards for children and young people with ASD when participating in research, there are various published guidelines focussing on the provision of such incentives for children and young people in general, (see Dorset Children's participation strategy 2010). These strategies emphasise that recognition for participation is crucial and they propose that the level of participation can be matched to various incentives/rewards. Participation that involves significant one off contribution is thought to warrant the provision of a voucher or ticket for an event. These guidelines stress the importance of asking the child/young person first whether such rewards/incentives would be beneficial to them as some children may find this aversive. In these cases alternative incentives such as certificates may be provided.

Equipment required and its availability
Further details: N/A

If students will be engaged a project involving children, vulnerable adults, one of the neurology patient panels or the psychiatric patient panel, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)
Further details: Clinical Supervision will be provided by one of the research collaborators (Dr Angela Brennan). The lead researcher is a current employee of the North Wales Clinical Psychology Programme (NWCPP) where training in clinical psychology practice is ongoing and monitored by the procedures of NWCPP

If students will be engaged in a project involving use of MRI or TMS, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)
Further details: N/A

What arrangements are you making to give feedback to participants? The responsibility is yours to provide it, not participants' to request it.
Further details: At the end of the interview, participants will be asked whether they would like feedback on the findings of the research. If they are interested, the researcher will note whether they would like the feedback via verbal communication (telephone) or post. Their preference will be noted. Once the data has been analysed and the internal report written, participants will be sent a copy of the report via post or verbal summary if they had said that they would like a copy (see attached documentation)

Finally, check your proposal conforms to BPS Guidelines on Ethical Standards in research and sign the declaration. If you have any doubts about this, please outline them.

Part 4: Research Insurance

Is the research to be conducted in the UK?
Yes

Research that is based solely upon certain typical methods or paradigms is less problematic from an insurance and risk perspective. Is your research based solely upon one or more of these methodologies? Standard behavioural methods such as questionnaires or interviews, computer-based reaction time measures, standardised tests, eye-tracking, picture-pointing, etc; Measurements of physiological processes such as EEG, MEG, MRI, EMG, heart-rate, GSR (not TMS or tCS as they involve more than simple 'measurement'); Collections of body secretions by non-invasive methods, venepuncture (taking of a blood sample), or asking participants to consume foods and/or nutrients (not including the use of drugs or other food supplements or caffine).
Yes

Confirmation of Bangor University Liability Insurance

Hasilwood House
60 Bishopsgate
London EC2N 4AW
Tel: 020 7847 8670
Fax: 020 7847 8689

TO WHOM IT MAY CONCERN

9th July 2012

Dear Sir/Madam

BANGOR UNIVERSITY
AND ALL ITS SUBSIDIARY COMPANIES

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following covers are currently in place:-

1. **EMPLOYERS' LIABILITY**

Certificate No.	Y016458QBE0112A/026
Period of Cover	1 August 2012 to 31 July 2013
Limit of Indemnity	£25,000,000 any one event unlimited in the aggregate.
Includes	Indemnity to Principals
Cover provided by	QBE Insurance (Europe) Limited and Excess Insurers.

2. **PUBLIC AND PRODUCTS LIABILITY**

Certificate of Entry No.	UM026/95
Period of Cover	1 August 2012 to 31 July 2013
Includes	Indemnity to Principals
Limit Of Indemnity	£50,000,000 any one event and in the aggregate in respect of Products Liability and unlimited in the aggregate in respect of Public Liability.
Cover provided by	U.M. Association Limited and Excess Cover Providers led by QBE Insurance (Europe) Limited

If you have any queries in respect of the above details, please do not hesitate to contact us.

Yours faithfully

Susan Wilkinson
For U.M. Association Limited

ISO 9001 REGISTERED FIRM

Confirmation Email of Bangor University Ethical Approval

Dear Pasquale

2013-9182 The experience of Anxiety for young people with ASD

Your research proposal number 2013-9182 has been reviewed by the School of 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.

Governance approval is granted for the study as it was explicitly described in the application and we are happy to confirm that this study is now covered by the University's indemnity policy.

If any new researchers join the study, or any changes are made to the way the study is funded, or changes that alter the risks associated with the study, then please submit an amendment form to the committee.

Yours sincerely

Everil McQuarrie

NHS Ethics Proposal: IRAS form

NHS REC Form | Reference: 13/WA/-0146 | IRAS Version 3.5

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 enter a short title for this project (maximum 70 characters)
The experience of "anxiety" for young people with ASD

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
[x] 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 review bodies are you applying to?

- ☑ NHS/HSC Research and Development offices
- ☐ Social Care Research Ethics Committee
- ☑ Research Ethics Committee
- ☐ National Information Governance Board for Health and Social Care (NIGB)
- ☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

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 NIGB Ethics and Confidentiality Committee 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):
The student is the lead researcher and is completing the project in part fulfilment of the Doctoral course in Clinical Psychology studying on the North Wales Clinical Psychology Programme.

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

13/WA/-0146

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

NHS
Health Research Authority

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 familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
The experience of "anxiety" for young people with ASD

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

REC Name:
NORTH WALES REC-WEST

REC Reference Number:
13/WA/-0146

Submission date:
06/05/2013

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

A qualitative analysis of the lived experiences of young people with Autism Spectrum Disorder (ASD) and co-morbid anxiety difficulties.

A2-1. Educational projects

Name and contact details of student(s):

Student 1

Title	Forename/Initials	Surname
Mr	Pasquale	Kornecki

Address	North Wales Clinical Psychology PROGRAMME (NWCPP)
	Brigantia Building
	Bangor, Gwynedd
Post Code	LL57 2DG
E-mail	pspf09@bangor.ac.uk
Telephone	07794457691
Fax	

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

Name and level of course/ degree:
Doctorate of Clinical Psychology

Name of educational establishment:
North Wales Clinical Psychology Programme - Bangor University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Angela	Brennan
Address	Camhs Clinic, Grounds of Glan Clwyd Hospital		
	Sarn Lane, Bodelwyddan		
Post Code	LL18 5UJ		
E-mail	angela.brennan@wales.nhs.uk		
Telephone	01745448670		
Fax			

Academic supervisor 2

	Title	Forename/Initials	Surname
	Dr	Gemma	Griffith
Address	School of Psychology		
	Brigantia Building		
	Penrhalt Road, Bangor		
Post Code	LL57 2AS		
E-mail	g.m.griffith@bangor.ac.uk		
Telephone	01248388067		
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 Mr Pasquale Kornecki	☑ Dr Angela Brennan ☑ Dr Gemma Griffith

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
	Mr	Pasquale	Kornecki
Post	Trainee Clinical Psychologist		
Qualifications	BSc Psychology MSc Psychological Research Methods		
Employer	North Wales Clinical Psychology Programme and Betsi Cadwaldr University Health Board		
Work Address	School of Psychology Brigantia Building		
Post Code	LL57 2DG		
Work E-mail	pspf09@bangor.ac.uk		
* Personal E-mail	paskornecki@googlemail.com		
Work Telephone			
* Personal Telephone/Mobile	07794457691		
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 R&D reviewers that is sent to the CI.

	Title	Forename/Initials	Surname
	Dr.	A	Brennan
Address	Camhs Clinic, Glan Clwyd Hospital, Sarn Lane, Bodelwyddan North Wales		
Post Code	LI18 5Uj		
E-mail	angela.brennan@wales.nhs.uk		
Telephone	01745448670		
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:
Protocol Version:
Protocol Date:
Funder's reference number:
Project website:

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 website of the National Research Ethics Service following the ethical review.*

The aim of this study is to explore the lived experiences of young people with ASD who have also been identified as having anxiety related difficulties where support for this has been given. Inclusion criteria is that the young person must have an established diagnosis of ASD and have received or currently be receiving support for anxiety related difficulties. Participants will be excluded if they have an identified learning disability or active psychosis/disorder of thought. Local ASD charities and support groups will be approached and meetings held to present the aims of the study and identify potential participants. In addition local CAMHS clinicians and Educational Psychologists will be contacted and informed of the study. Professionals will contact potential participants and gain their consent for contact to be made by the lead researcher. A maximum of 15 young people aged between 11-18 years will be interviewed by the lead researcher. In addition, they will complete an anxiety diary over a period of a week prior to the interview. This diary will encourage the individual to record thoughts, feelings and physical sensations present during an episode of anxiety along with any coping strategies used and is considered a less intrusive approach to data collection than a semi structured interview as individuals may feel more comfortable filling in a diary in private on their own. Interviews and diaries will later be analysed using Interpretative Phenomelogical Analysis (IPA; Smith, Harman & Osborne, 1999). IPA is a form of analysis where interviews are transcribed and then themes from both individual and collated interviews are identified. Themes will focus on how individuals make sense of their experiences of ASD and anxiety. A summary of the overall findings will be disseminated to individuals at their request, when the study is completed.

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.

Participant recruitment:

A multi-modal recruitment strategy will be adopted. Following a number of presentations to professionals and carers regarding the nature of the study, examples of where participants will be recruited may include but will not be limited to the following:

- Child and Adolescent Mental Health Services (CAMHS) across North Wales
- Autism charities (e.g. National Autistic Society groups and Autism Initiatives)
- Educational Psychologists working across North Wales

Voluntary Organisations who are involved with families with young people who have ASD (e.g. Jigsaw, Social Smiles)

According to the National Public Health Service for Wales (2009) there are approximately 162,000 children and young people between the ages of 5-24 years living in North Wales. The National Autistic Society (NAS) suggest that the best estimate for ASD prevalence in children is 1 in 100. Therefore based on the above figures one can expect to find approximately 1,620 children with a diagnosis of ASD in North Wales.

It is thought that 15 participants would be sufficient in order to retain an idiographic focus. Smith et al (1999); Smith (2004) have argued the advantages of smaller sample sizes (10 being the maximum), however after reviewing the IPA literature Reid, Flowers and Larkin (2005) suggest that the mean number of participants in IPA studies is 15 and can be as large as 42. Due to the fact that sometimes children with ASD may find it difficult to participate in long indepth interviews and for various reasons may struggle to answer questions in great detail, recruiting a slightly larger number may ensure that the quality and depth of data is high.

Inclusion Criteria
Inclusion criteria will be as follows:
1) Young people aged between 11-18years with a diagnosis of ASD.
2) Participants will have received or currently be receiving support, either through NHS or non-NHS organisations for anxiety related difficulties. It is likely that some cases will be currently receiving input. In some instances cases may be closed to CAMHS but open for medication review or receiving active intervention from other services such as Educational Psychology (EP). Cases accessed through EP, or autism charities may not be open to CAMHS but still approached through the recruitment process.

Age Criteria:
Young people will be of secondary school age ranging from 11 years to 18 years.

Exclusion Criteria:
The presence of an identified learning disability will be an exclusion criterion. A further exclusion will be the presence of an additional mental health problem that may affect the young person's ability to participate in the interview process (e.g., active psychosis).

Even though information and consent materials will be provided in Welsh and English, participants will only be included if they are willing to be interviewed in English. This is because there are no resources available for interviewing in Welsh, and the qualitative analyst is only able to work through the medium of English.

Participant Ethical considerations:

Given that the some participants may fall within the 11 -15 years age bracket, parental consent will be required as well as agreement from the young person. For those participants that are aged 16 years or older consent will be sought from the individual themselves via letter. However for those aged 16 years or older it is likely that gaining parental agreement will be necessary when arranging to visit the young person in their home. Information will be provided to parents within the information pack provided to the young person. Given that the presence of an identified Learning Disability is considered an exclusion criteria for this current study it is assumed that capacity to give consent will not be compromised. On meeting the young person, their capacity and willingness to consent will be assessed by reminding them about the purpose of the study and checking they still wish to take part.

Data management and analysis:

All data gathered would be anonymised with identifiers removed to ensure confidentiality. Data will be stored on a password protected secure USB drive as per BCUHB and NWCPP policy until the completion of the project. The data will be archived as per policy.

Feedback:

At the end of the interview participants will be offered the option to receive feedback at the end of the study. This will be provided either via telephone or through the post.

Feedback to young people and their parents is important. When considering this it is important to gain consent regarding the dissemination of such information. Children in the older age category may not wish for their parents to be made aware of their specific contribution, but the overall findings of the study will be shared. This can be discussed at the early stages of their involvement in the project.

Verbal feedback will be specifically tailored to young people and a summary report will also be provided for each participant again written so that it is accessible to the young person. Parents / carers will also receive a copy. Written information regarding the outcomes of the study will be provided to the local CAMHS and other agencies that participate (i.e. local NAS, Autism Outreach Service, Educational Psychology Service, Voluntary Organisations).

Risk assessment:

Local lone working policy (BCUHB policy) will be implemented when undertaking interviews with the young people. Initial conversations via telephone will be held with young people and their parents interested in taking part in the

project about how and where they would like to be interviewed. Wherever possible the lead researcher will endeavour to fit in with the needs and requirements of the young person and their parent/carer. This will include being flexible around interview location with options including the individual's home, school, local GP surgery or local CAMHS clinic. Opportunity for parents to be present during these will be given to each participant with the expectation that parents will be at the family home when interviews occur there.

Given the nature of the research there is potential for some participants to find some of the questions sensitive. However previous research involving direct interviews with young people and adults with high functioning autism or Asperger syndrome and anxiety related difficulties suggest that participants do not typically become distressed, see Humphrey's and Lewis 2008 who used IPA to look at the views of young people with ASD in mainstream secondary education. Anxiety was suggested to be linked with high levels of stress along with the demands on social contact and integration that secondary schools place on young people; something that young people with ASD may find more challenging. The present study adopts a similar data collection process as seen in Humphrey and Lewis (2008) whereby a more potentially intrusive semi-structured interview is accompanied by the completion of a potentially less intrusive experience diary. Prior to commencing the interview a Spence anxiety questionnaire will be delivered to provide some contextual information about the young person's current level of anxiety. This questionnaire will be scored within 48 hours of completion and the results discussed with the supervisory team. If a concern is raised at this point then the parents of the young person will be contacted where there will be a potential to give advice about where to find the most appropriate support.

Particular attention will be paid to this during the process with regular breaks and time given to the young person. If requested by the young person, a parent can be present during the interview. In addition it will be explicitly mentioned that the child can choose to stop the interview for any reason by asking the interviewer to do so, after which reassurance and support will be provided to the young person.

If during the interview the young person gives information indicating that they or someone else is at risk of significant harm, BCUHB and All Wales Policy for safeguarding children will be followed. If there are any concerns in relation to risk of harm, supervision from the clinical supervisor will be sought.

If they are in school and there are any concerns about the young person's well being, the researcher can liaise with the designated member of the teaching staff who are level two trained in recognising and supporting children who experience mental health difficulties. These particular members of staff have procedures to follow in the event of a child requiring such support, which can involve contacting CAMHS.

In the unlikely event of any child becoming distressed as a result of the interview process the lead researcher can liaise with the young persons's parent or carer and a member of the supervision team. It is also important to spend some time following the interview to find out how the young person feels and if there are any issues that need addressing. This will be done verbally immediately after the interview, or if this is not possible a follow up telephone conversation. If the child becomes distressed during an interview that takes place,parents will be informed.

Supervision will be regularly used in order to be mindful of any issues relating to the wellbeing of the researcher given the nature of the topic. There are also support networks that can be accessed through NWCPP. At the beginning of each interview information will be provided regarding BCUHB policy on confidentiality and its limitations regarding concerns over harm to self or others.

Data storage:

For the duration of the project any hard paper copies containing confidential information will be stored at Denbighshire CAMHS in a secure filing cabinet. Digital recordings will be stored on a memory card, which will be kept in a locked filing cabinet. Additional copies of audio files will be kept on a secure drive within Denbighshire CAMHS.

Upon completion of the project, September 2014, feedback on the overall findings of the study will be provided to parents and children (if they opted to receive feedback) as well as to the professionals and agencies who were involved. Once the project has been approved by NWCPP hard copies of data with identifiers will be destroyed in accordance with BCUHB policy. Anonymised data such as transcripts will initially be held for a period of up to 5 years to allow for re-analysis and to account for timescales for publication. These transcripts will be stored at NWCPP, 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.*

Very little is known about how anxiety is experienced by young people who have a diagnosis of ASD in relation to how anxiety influences their thinking, feelings and physical experiences. Therefore this is a qualitative study to gain an understanding of the experience of anxiety in young people diagnosed with Autistic Spectrum Disorder (ASD)through the use of semi structured interviews to allow individuals to talk about their experiences.

1 in 150 children and young people typically have severe deficits in social communication and restricted interests (Centres for Disease Control, 2007) with anxiety related symptoms being amongst the most common comorbid difficulty found in children and adolescents with ASD (Ghazzihudin, 2002). Given this relatively high prevalance rate of ASD and anxiety related difficulties in children it seems appropriate to gain a greater understanding of what this means for those young people living with these difficulties. This can include the direct lived experience of the individual but also focussing on their experiences of treatment/support for such anxiety related difficulties. This in turn may inform how best to approach such difficulties with individuals to tailor them effectively, (Humphries & Lewis, 2008).

Research in this field has typically focussed on the accounts of parents or care-givers of the young person or used standardised measures such as questionnaires to elicit information from the young person themselves. The use of such standardised measures may not capture the individual nuances of living with such difficulties, therefore a less restrictive qualitative approach may be a more appropriate method of analysis to gain a deeper understanding of the young persons experiences.

There is qualitative research looking into the experiences of children with ASD, in particular looking at social interaction and friendships (Daniel & Billingsley, 2010). In addition more recent studies have looked at parental/caregiver understandings of the relationship between their child's anxiety and ASD (Ozsivadjian, Knott & Magiati, 2012), however qualitative research focusing on the interaction between ASD and anxiety in young people does not seem to have been conducted with a specific focus on the young people themselves.

From a theoretical perspective, the views of young people themselves may lead to a quite different understanding of anxiety within ASD and even different ways of assessing/measuring and understanding the severity of anxiety "symptoms". Given the importance for including service users in the development of services and treatment interventions it is also important to gain an understanding of such subjective experiences in order to shape future services effectively. It is for these reasons that the current project has been developed.

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

N/A

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

ASD may occur in approximately 1 in 150 children/adolescents, who typically have severe deficits in social communication and restricted interests (Centres for Disease Control, 2007).

Anxiety related symptoms are amongst the most common comorbid difficulty found in children and adolescents with ASD (Ghazzihudin, 2002). In support of this a review completed by White, Oswald, Ollendick and Scahill (2009b) suggested that between 11% and 84% of children with ASD also experience some anxiety impairments with phobia, generalised anxiety and Obsessive Compulsive Disorder being the most common reported. Given this it seems crucial to gain a deeper understanding of the effectiveness and treatment of anxiety disorders in those children with ASD (Lord et al, 2005).

It has been hypothesized that the levels of stress likely to contribute to such anxiety may stem from the difficulties with social reasoning and for some individuals specific learning disabilities that are associated with ASD (Sofronoff et al, 2005). This was later supported by a qualitative study looking at the lived experiences of children with ASD in mainstream education (Humphries & Lewis, 2008). In relation to a child's understanding of ASD they found informative themes with children holding quite a range of views using terms such as "bad brain" and referring to ASD as part of their identity.

When considering anxiety in the presence of ASD it is clear that an individual's awareness is important when considering their experienced level of difficulty. Atwood (2000) suggests that an individual's awareness of their level of social disconnectedness may contribute to the impact social isolation has on anxiety. Therefore having a comorbid anxiety disorder could compound the social impairment experienced as a result of ASD (White et al, 2009), contributing to social avoidance or awkward interactions with peers (Myles, Barnhill, Hagiwara, Griswold & Simpson, 2001).

When considering the evidence base available it would seem that the vast majority of empirical data relating to anxiety in children with ASD are mostly focused on using standardized measures of either child or parent reports. Whilst standardized measures (Spence Anxiety QUestionnaire) are considered valid and reliable ways to measure symptomology there are also limitations. James et al (1994) have argued that some measures of fear and anxiety can be particularly problematic as they are not situation-specific but measure anxiety in more general terms, especially given that although children with ASD experience similar themes associated with anxiety compared to typically developed children, there are key differences that are sometimes missed (Howlin, 1998; Gillot, Furniss & Walter, 2001). This suggests that the use of standardized measures alone may not capture the individual nuances that can provide deeper understandings of the subjective nature of anxiety in those children with ASD.

What is noteworthy is that the majority of research into ASD and anxiety in young people investigates subtypes and prevalence, with very little focus on the subjective nature of experiencing anxiety on the part of the young person. In addition to this very little is known about the experience of receiving treatment and support for such difficulties over and above standardized outcome measures that indicate treatment efficacy.

From a theoretical perspective, the views of young people themselves may lead to a quite different understanding of anxiety within ASD and even different ways of assessing/measuring and understanding the severity of anxiety "symptoms". Given the importance for including service users in the development of services and treatment interventions it is also important to gain an understanding of such subjective experiences in order to shape future services effectively. It is for these reasons that the current project has been developed.

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.*

As very little is known about the perspectives of anxiety in young people with ASD, the research is exploratory. Therefore, a qualitative, interview approach is taken in order to gather rich information from participants about their experiences and perceptions of the ASD and anxiety.

Once ethical approval has been gained recruitment will begin immediately. This is expected to be April 2013.

Stage 1: Initial meetings will be held with local CAMHS teams, Educational Psychologist working within North Wales

and local ASD support groups (e.g.National Autistic Society (NAS) and Autism Initiatives) and voluntary organisations (Jigsaw, Createasmile) across North Wales. Where cases have been closed to professionals working with them a specific cover letter will be sent to the family signed by the professional asking if they would like to take part in the study (see attached document.) The purpose of these meetings is to promote the research and allow professionals to consider whether they are aware of any potential participants. Professionals will be given clear inclusion/exclusion criteria and asked to identify potential suitable participants from their previous or current case loads. The lead researcher will attend support group meetings and hand out information packs, opt in forms and a covering letter to those that are interested in taking part in the study. At this stage the lead researcher will discuss the exclusion and inclusion criteria with the parents in attendance. If there are any concerns or queries at this stage regarding exclusion criteria then participants will not be included in the study at this time. According to the National Public Health Service for Wales (2009) there are approximately 162,000 children and young people between the ages of 5-24 years living in North Wales. NAS suggest that the best estimate for ASD prevalence in children is 1 in 100. Therefore based on the above figures one can expect to find approximately 1,620 children with a diagnosis of ASD in North Wales. It is thought that 15 participants would be sufficient. This number is greater than normally expected for an interpretative Phenomenological Analysis (IPA), however due to the fact that sometimes children with ASD may find it difficult to participate in long in depth interviews and for various reasons may struggle to answer questions in great detail, recruiting a larger number may ensure that the quality and depth of data is high.

Stage 2: The professionals are then invited to contact the young person and their family and discuss the nature of the study by inviting them either to their local clinic for a face-to-face discussion, contacting them via telephone or visiting them at their home. The purpose of this is to see if they want to opt in to the study which means that they agree to the lead researcher sending them more detailed information about the study through the post (see attached documents). Within this information will be a consent form and a stamped addressed envelope.

Stage 3: Upon receipt of signed consent forms the lead researcher will telephone the family to arrange to meet. During this phone call it is hoped that the lead researcher will speak to both the parents and the young person themselves. In addition further question about inclusion and exclusion criteria will be discussed with parents and/or the young person themselves.

Stage 4: A letter will be sent to the young person and their family to confirm the date of the interview. With this an anxiety experience diary (see attached forms) will be enclosed with instructions on how to complete this. This diary sheet is for the participant, (if agreeable) to keep a record of experiences of anxiety over a period of one week using a specially designed diary format (see attached documents). These will be collected on the day of the interview.

Stage 5: Individual meetings will be arranged with the young person (and parents if the young person wants them there) at a site of their choosing (home, school, CAMHS clinic or GP surgery)approximately one week after receiving the anxiety diary. Prior to the interview starting the Spence Anxiety questionnaire will be completed and the semi structured interview will be carried out with the young person, (see attached documentation). It is hoped that a semi-structured interview format will enable some comparability and containment for the participant, whilst enabling scope to explore further any areas which may be of importance or interest. The flexibility of the interview format will also help to build rapport with the participants, which is important when exploring a sensitive area such as this. Expected time frame to begin interviews is June 2013. The lead researcher will go over the areas on the participant information sheet which concern consent, agreement to be recorded and the participants right to withdraw from the interview at any time. At the beginning of the interview the lead researcher will also explain that everything discussed is confidential, unless they disclose information which the lead researcher feels poses a risk of harm to themselves or others. If this situation occurs the lead researcher will discuss their concerns with the participant, before passing the information on to the participants parents and provide information to them about services that may be able to offer support. Participants will be given the opportunity to ask any questions and then a Spence anxiety questionnaire will be delivered to provide some contextual information about the young persons current level of anxiety. (This questionnaire will be scored within 48 hours of completion and the results discussed with the supervisory team. If a concern is raised at the time of scoring the questionnaire then the parents of the young person will be contacted where there will be a potential to give advice about where to find the most appropriate support.) The lead researcher will test the digital voice recorder to ensure it is working correctly and commence the interview.

Stage 6: Analysis of both interview transcripts and experience diaries will occur in parallel with stage 5. As soon as interviews are completed transcripts will start to be analysed. The same applies to the completion and submission of experience diaries. Interviews will analysed using Interpretive Phenomenological Analysis (IPA). Following analysis feedback will be provided either through the post in the form of a written report or by telephone contact with the family and the young person.

Final analysis is hoped to be completed by January 2014 with a draft report completed by March 2014. Feedback to Parents and Young people will be in April 2014 with a final submission date of the project in June 2014.

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?

- [x] Design of the research
- [x] Management of the research
- [x] Undertaking the research
- [ ] Analysis of results
- [x] Dissemination of findings
- [ ] None of the above

Give details of involvement, or if none please justify the absence of involvement.
Management and Design of the research:
The research team will be consulting with Jigsaw and Createasmile about the project - these groups do not involve professionals but are support groups which comprise parents and carers of children and young people with ASD who are or who have been users of services

Undertaking the research:
The lead researcher will be linking in with users of services and their parents/carers to undertake the research project

Dissemination of findings:
The lead researcher will feed back the overall findings of the study to patients, past and present users of services and their carers and to professionals and organisations who work with them

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

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

Inclusion criteria will be young people with a diagnosis of ASD who have been identified as experiencing anxiety related difficulties where intervention for anxiety related difficulties has been provided. It is likely that some cases will be currently receiving input from CAMHS. In some instances cases may be closed to CAMHS but open for medication review or receiving active intervention from other services such as Educational Psychology. Cases accessed through Educational Psychology and local support groups such as NAS and autism initiatives may not be open to CAMHS but still approached through the recruitment process. Young people will be of secondary school age ranging from 11 years to 18 years.

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

The presence of an identified learning disability will be an exclusion criterion. A further exclusion criterion will be the presence of an additional mental health problem that may affect the young person's ability to participate in the interview process (e.g., active psychosis).

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

Seeking consent	1	0	30 mins	Postal information to potential participant's home sent by lead researcher. In addition to this a telephone conversation will be carried out by the lead researcher to the young persons home.
Interview	1	0	1 hour	The lead researcher will carry out the interview. This will be either in the local CAMHS clinic, GP surgery, home or school.
Questionnaire (Spence)	1	1	10 mins	The lead researcher will deliver the Spence anxiety questionnaire.
Feeding back findings of research (if individual appointment is requested)	1	0	30 mins	The lead researcher will provide feedback via telephone contact or via written report.
Completion of Diary to record episodes of anxiety	1	0	7 days	The lead researcher will provide information regarding the purpose and process of completing the diary. If completed this will be returned to the research team via Stamped Addressed Envelope or handed in to the lead researcher on the day of the interview
opt in form	1	0	15	Professionals in contact with individuals (camhs clinicians, ed psych or support group staff) would discuss study (and hand cover letter and the information sheets provided by the lead researcher) to the family and young person and ask if they would sign the opt in form in order for lead researcher to send further information and gain consent.

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

It is expected that the time frame from consent to feedback will be 12 months.

Participants will be contacted within two weeks of their returning the consent/opt in form to the lead researcher. The research worker will contact participants using the details the participants provided. The research worker will talk with the participant to arrange a time for the interview suitable for them. This is anticipated to be within two weeks of first contact by the researcher to arrange a time. As the interview time will be at participants' convenience, we do not know exactly when they will take place. However it is expected that this will be no longer than six weeks after returning the consent form. The interview will be the last contact with the research team (with the exception of being posted the results of the project, which will happen once the data has been collected and analysed and sent only if the participant had indicated they would like the results sent to them).

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.

There are practical considerations for participants such as travel requirements. The lead researcher will endeavour to be as flexible as possible to minimise such expectations. It is thought that the lead researcher can reimburse participants for all travel linked to taking part in the research. As well as this a £10 voucher, appropriately selected based on the individual, will be presented as a thank you for taking part in the research. The provision of such a token of thanks will be mentioned in the initial information about the study so that participants are aware that this will occur. Participants will be given a choice in the consent form that they return of what type of voucher they would like to receive (or the option to receive a certificate if receiving a voucher is too aversive).

Local lone working policy (BCUHB policy) will be implemented when carrying interviews with the children. Initial conversations via telephone will be had with young people and their parents interested in taking part in the project about how and where they would like to be interviewed. Wherever possible the lead researcher will endeavour to fit in with the needs and requirements of the young person. This will include being flexible around interview location with options including the individual's home, school, local GP surgery or local CAMHS clinic. Opportunity for parents to be present during these will be given to each participant with the expectation that parents will be at the famly home when interviews occur there.

Given the nature of the research there is potential for some people to find some of the questions sensitive, however previous research involving direct interviews with young people and adults with high functioning autism or Asperger syndrome suggest that participants do not typically become distressed.

Particular attention will be paid to this during the process with regular breaks and time given to the young person. If requested by the young person, a parent can be present during the interview. In addition it will be explicitly mentioned that the child can choose to stop the interview for any reason by asking the interviewer to do so, after which reassurance and support will be provided to the young person, with a follow-up telephone call delivered in the event of an interview termination due to distress. This is likely to occur following discussion with the supervisory team up to 48 hours after the event.

If during the interview the young person gives information indicating that they or someone else is at risk of significant harm, BCUHB and All Wales Policy for safeguarding children will be followed. If there are any concerns in relation to risk of harm, supervision from the clinical supervisor will be sought.

If they are in school and there are any concerns about the young person's well being, the researcher can liaise with the designated member of the teaching staff who are level two trained in recognising and supporting children who experience mental health difficulties. These particular members of staff have procedures to follow in the event of a child requiring such support, which can involve contacting CAMHS.

In the unlikely event of any child becoming distressed as a result of the interview process the lead researcher can liaise with a member of the supervision team. It is also important to spend some time following the interview to find out how the young person feels and if there are any issues that need addressing. This will be done verbally immediately after the interview, or if this is not possible a follow up telephone conversation. If the child becomes distressed during an interview that takes place,parents will be informed.

Supervision will be regularly used in order to be mindful of any issues relating to the wellbeing of the researcher given the nature of the topic. There are also support networks that can be accessed through NWCPP. At the beginning of each interview information will be provided regarding BCUHB policy on confidentiality and its limitations regarding concerns over harm to self or others.

If participants do become distressed, the interviewer will:
• Offer to terminate the interview.
• Remind the participants of their right to withdraw.
• Provide support in the form of listening and reassuring the interviewee.
• Offer to give families information about potential points of contact that may be able to offer support (e.g. local support networks, clinicians in their local health board).

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 focus on how young people with ASD and anxiety related difficulties experience anxiety. they will concentrate on living with anxiety and therefore will have a focus on thoughts and feelings as well as physical experiences. in addition participants will be asked to reflect on the interventions and support they have received for anxiety. These questions do include topics that some people may find sensitive, although there is a minimal risk that some participants may be distressed by them. However, if participants do become distressed, the interviewer will:
• Offer to terminate the interview.
• Remind the participants of their right to withdraw.
• Provide support in the form of listening and reassuring the interviewee.
• Offer to give families information about potential points of contact that may be able to offer support (e.g. local support networks, clinicians in their Local Health Board).

The questions are not expected to elicit disclosure of information that could require notification or other followup action by the researcher.

However, if participants do disclose information that could require notification or other followup action by the interviewer, he will notify and discuss the matter with Dr. Angela Brennan in the first instance, and then together they will decide what action to take, if any. Dr. Angela Brennan is an experienced Principal Clinical Psychologist and is the Lead Psychologist within Denbighshire CAMHS.

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

This research gives participants the opportunity to share their experiences of having ASD and Anxiety. The interviews

are semi structured so give the opportunity for participants to talk about issues that are important to them.

They will be aware (from information on the provided information sheet) that their experiences will contribute to the feedback process which will aim to improve understanding of living with ASD and anxiety for future young people.

the interviews may also serve to remind individuals of the interventions and support that they have received helping them to remember what has helped in the past. conversations will also be had regarding who they can turn to for future support. such signposting will be helpful for both the young person and their parents alike.

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

Due to the fact that interviews will potentially take place in family homes and sites such as schools and GP clinics that are unfamiliar to the researcher local lone working policy (BCUHB policy) will be implemented when carrying interviews with the young people in these settings. The lead researcher will also make attempts to visit the GP clinics and schools prior to the interview to select the most appropriate room in terms of safety and comfort for all involved.

Supervision will be regularly used in order to be mindful of any issues relating to the wellbeing of the researcher given the nature of the topic. There are also support networks that can be accessed through NWCPP.

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).*

Once ethical approval has been gained recruitment will begin immediately. This is expected to be April 2013.

Stage 1: Initial meetings will be held with local CAMHS teams, Educational Psychologist working within North Wales and local ASD support groups (e.g.National Autistic Society (NAS) and Autism Initiatives) and voluntary organisations (Jigsaw, Createasmile) across North Wales. Where cases have been closed to professionals working with them a specific cover letter will be sent to the family signed by the professional asking if they would like to take part in the study (see attached document.) The purpose of these meetings is to promote the research and allow professionals to consider whether they are aware of any potential participants. Professionals will be given clear inclusion/exclusion criteria and asked to identify potential suitable participants from their previous or current case loads. The lead researcher will attend support group meetings and hand out information packs, opt in forms and a covering letter to those that are interested in taking part in the study. At this stage the lead researcher will discuss the exclusion and inclusion criteria with the parents in attendance. If there are any concerns or queries at this stage regarding exclusion criteria then participants will not be included in the study at this time. According to the National Public Health Service for Wales (2009) there are approximately 162,000 children and young people between the ages of 5-24 years living in North Wales. NAS suggest that the best estimate for ASD prevalence in children is 1 in 100. Therefore based on the above figures one can expect to find approximately 1,620 children with a diagnosis of ASD in North Wales. It is thought that 15 participants would be sufficient. This number is greater than normally expected for an interpretative Phenomenological Analysis (IPA), however due to the fact that sometimes children with ASD may find it difficult to participate in long in depth interviews and for various reasons may struggle to answer questions in great detail, recruiting a larger number may ensure that the quality and depth of data is high.

Stage 2: The professionals are then invited to contact the young person and their family and discuss the nature of the study by inviting them either to their local clinic for a face-to-face discussion, contacting them via telephone or visiting them at their home. The purpose of this is to see if they want to opt in to the study which means that they agree to the lead researcher sending them more detailed information about the study through the post (see attached documents). Within this information will be a consent form and a stamped addressed envelope.

Stage 3: Upon receipt of signed consent forms the lead researcher will telephone the family to arrange to meet. During this phone call it is hoped that the lead researcher will speak to both the parents and the young person themselves.In addition further question about inclusion and exclusion criteria will be discussed with parents and/or the young person themselves.

Stage 4: A letter will be sent to the young person and their family to confirm the date of the interview. With this an anxiety

experience diary (see attached forms) will be enclosed with instructions on how to complete this. This diary sheet is for the participant, (if agreeable) to keep a record of experiences of anxiety over a period of one week using a specially designed diary format (see attached documents). These will be collected on the day of the interview.

Stage 5: Individual meetings will be arranged with the young person (and parents if the young person wants them there) at a site of their choosing (home, school, CAMHS clinic or GP surgery)approximately one week after receiving the anxiety diary. Prior to the interview starting the Spence Anxiety questionnaire will be completed and the semi structured interview will be carried out with the young person, (see attached documentation). It is hoped that a semi−structured interview format will enable some comparability and containment for the participant, whilst enabling scope to explore further any areas which may be of importance or interest. The flexibility of the interview format will also help to build rapport with the participants, which is important when exploring a sensitive area such as this. Expected time frame to begin interviews is June 2013. The lead researcher will go over the areas on the participant information sheet which concern consent, agreement to be recorded and the participants right to withdraw from the interview at any time. At the beginning of the interview the lead researcher will also explain that everything discussed is confidential, unless they disclose information which the lead researcher feels poses a risk of harm to themselves or others. If this situation occurs the lead researcher will discuss their concerns with the participant, before passing the information on to the participants parents and provide information to them about services that may be able to offer support. Participants will be given the opportunity to ask any questions and then a Spence anxiety questionnaire will be delivered to provide some contextual information about the young persons current level of anxiety. (This questionnaire will be scored within 48 hours of completion and the results discussed with the supervisory team. If a concern is raised at the time of scoring the questionnaire then the parents of the young person will be contacted where there will be a potential to give advice about where to find the most appropriate support.) The lead researcher will test the digital voice recorder to ensure it is working correctly and commence the interview.

Stage 6: Analysis of both interview transcripts and experience diaries will occur in parallel with stage 5. As soon as interviews are completed transcripts will start to be analysed. The same applies to the completion and submission of experience diaries. Interviews will analysed using Interpretive Phenomenological Analysis (IPA). Following analysis feedback will be provided either through the post in the form of a written report or by telephone contact with the family and the young person.

Final analysis is hoped to be completed by January 2014 with a draft report completed by March 2014. Feedback to Parents and Young people will be in April 2014 with a final submission date of the project in June 2014.

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:

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?

Initial meetings will be held with local CAMHS teams, Educational Psychologist working within North Wales and local ASD support groups (e.g.NAS and Autism Initiatives) across North Wales. The purpose of these meetings is to promote the research and allow professionals to consider whether they are aware of any potential participants. Professionals will be given clear inclusion/exclusion criteria and asked to identify potential suitable participants from their previous or current case load. If a case is closed to a professional then a specific cover letter can be sent to families signed by the professional asking if they would like to opt in to the study.

The professionals are then invited to speak to the young person and their family and discuss the nature of the study. The purpose of this is to see if they want to opt in to the study and therefore agree to the lead researcher to send them more detailed information about the study through the post (see attached documents). Within this information will be a consent form and a stamped addressed envelope. Upon receipt of consent forms the lead researcher will telephone the family to arrange to meet. During this phone call it is hoped that the lead researcher will speak to both the parents and the young person themselves in order to gain consent.
With regards to recruiting from support groups such as NAS or Autism initiatives, the lead researcher will gain consent from the organisations to attend their meetings. whilst at the meeting the lead researcher will present the study and hand out information sheets and opt in forms along with stamped addressed envelopes to the group members. The

same procedure will then apply as above, once opt in forms have been received.

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.

Professionals will approach individual families based on their knowledge of the difficulties faced by that individual through working with them. Professionals will have had clear inclusion/exclusion criteria explained to them and will have information packs and opt-in forms to give to the families. They will then meet with the young person and/or their family to briefly outline the study. Parents and the young people can then give consent to opting in to the study which means that they agree to the lead researcher to contact them with more detailed information about the study. This will be done by sending detailed participant information sheets and consent forms along with information about the researcher and the study. Parents and Young people can then choose to send back the consent form or not. By sending back the form in the stamped addressed envelope provided the research team assume that consent has been given. at the beginning of each interview a preamble will be read that details confidentiality the right to withdraw consent and information about the purpose and nature of the study. The lead researcher will make several efforts to remind the participants of these important ethical issues at each stage of contact.

In relation to those participants recruited through support groups parents and young people will have had information sheets describing the study and will have had the opportunity to ask the lead researcher questions at the group meetings. Once opt in forms have been received the same process as in the above paragraph will apply.

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?

Participants can return the consent form at any point of the duration of data collecting (anticipated to be 6 months, June 2103-November 2013). We do ask them to return the form within two weeks if possible, however, the end date of the recruitment period will be put on the information pack so participants can contact the research team at any point during the recruitment period. They will be under no pressure to make a decision quickly.

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 will be provided bi-lingually but unfortunately the resources are not available to be able to offer bilingual interviews. The interview schedule has been devised under the supervision of Dr Gemma Griffith who has lots of experience at conducting and using IPA to analyse such interviews with adults and young people with ASD. It is therefore thought the interview questions/protocol will not only be appropriately selected but suit the methodology for analysis.

During the recruitment stage a telephone conversation will be made by the lead researcher to the family to arrange the interview. It is thought that at this stage attempts will be made to speak to the young person themselves and allow them to ask questions. Given one exclusion criteria is the presence of an identified Learning Disability it is expected that the young person will have a working knowledge and understanding of language. However discussion with the parents will provide further information regarding this. The use of pictures and simple text will be chosen in order to ensure clarity (see attached documents).

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?

Welsh translations of all information sheets will be given to participants. The information sheets will be translated pending approval for the ethics board.

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:

The parent or young person can let the research team know if they choose to withdraw from the research at any point.

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
- ☐ 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 including X−rays
  - ☑ NHS computers
  - ☑ Home or other personal computers
  - ☑ University computers
  - ☐ Private company computers
  - ☐ Laptop computers

Further details:
Use of personal information such as addresses and emails:

This information will not be known to the researchers until contacted by participants or the participants have returned the consent form with the contact details they would like the researcher to use (e.g. phone number or email). The contact details will not be shared with anyone outside the named research team.

Publication of direct quotations from respondents:

All direct quotes from participants, when written up for publication or for internal reports will be made anonymous, either with a participant number or a pseudonym. Any potentially identifying information (e.g. names of professionals or places) will also be removed.

Use of audio/visual recording devices:

A digital recorder will be used to record the interviews. Written consent will be sought (see consent form) and the participant will again be asked for verbal permission to record the interview just before it commences. After the interview has finished, it will be securely downloaded onto the researchers University computer, the file given a number to ensure anonymity, and the interview will be deleted from the digital recorder once the download is complete to enhance security.

Storage of personal data on any of the following:
Manual files (includes paper or film):

The consent forms will have the contact information of the participants on them, and will be stored at Bangor University in a locked filing cabinet. Each participant will be given an identification number that will be written on the consent form. Thereafter all digital data will refer to this identification number, to keep the identity of participants anonymous. The only way of matching a digital file to a participant's name will be by referring to the manual files.

University computers:

The university computer is password protected. The digital files from the interviews will be stored on a university computer, each file will be password protected. Each interview will be given a number which can be linked to participants only via the consent forms (which will be in a locked cabinet within Bangor University). Additionally, the transcripts of the interviews will be stored on a university computer, the files will be stored using the identification number. In addition data is likely to be stored on a university selected secure USB pen drive. This is password encrypted and data files will be given a number to ensure anonymity.

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.*

The BCUHB policy on confidentiality will be adhered to at all times. Participants will not be identifiable either from computer records or written reports/publications. All direct quotes from participants, when written up for publication or reports will be made anonymous, either with assigned numbers or a pseudonym. Any potentially identifying information (e.g. names of professionals or places) will also be removed.

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.*

If applicable, the direct clinical care team will have access as per their usual role. The research team (lead researcher and supervisory team) will have access to contact information participants chose to provide on their consent form. The research team will not have access to case files or any other information other than given on the consent form. No outside monitors or auditors will require access to participant 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.
For participation a £10 voucher or certificate (identified by the individual in the initial consent form) will be provided for each young person; this will be covered within the NWCPP budget. Whilst there does not appear to be any published guidelines specifically focussing on the provision of incentives/rewards for children and young people with ASD when participating in research, there are various published guidelines focussing on the provision of such incentives for children and young people in general, (see Dorset Children's participation strategy 2010). These strategies emphasise that recognition for participation is crucial and they propose that the level of participation can be matched to various incentives/rewards. Participation that involves significant one off contribution is thought to warrant the provision of a voucher or ticket for an event. These guidelines stress the importance of asking the child/young person first whether such rewards/incentives would be beneficial to them as some children may find this aversive. In these cases alternative incentives such as certificates may be provided.

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.
The research will not be registered on a public database as it is not publically funded. It will be registered on the BCUHB database and once complete it will be available in the University of Bangor library. It is the intention of the lead researcher to ensure that the work be written up for publication in a scientific journal

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:*

- [x] Peer reviewed scientific journals
- [ ] Internal report
- [x] 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)

Written information about the overall findings of the study provided to:
young people who participated and their parents / carers if they express an interest to receive feedback.
all north wales camhs
local professionals and agencies who participated (NAS, Educational Psychologists, Jigsaw, Social Smiles, Autism Initiatives)

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.
At the end of the interview, participants will be asked whether they would like feedback on the findings of the research. If they are interested, the researcher will note whether they would like the feedback via verbal communication (telephone) or post. Their preference will be noted. Once the data has been analysed and the internal report written, participants will be sent a copy of the report via post or verbal summary if they had said that they would like a copy

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
- [x] Review within the Chief Investigator's institution or host organisation
- [x] 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 NWCPP has received and approved an initial research proposal for this study. The research team comprises of a number of experienced researchers in the field of psychology. The research will also be reviewed by members of the School of Psychology's ethics board at Bangor University before receiving wider NHS ethics and R&D approval.

The study has also been reviewed within the research team by the two supervisors and the lead researcher undertaking their doctoral qualification. This is an ongoing process as the research will continue to be discussed by the research team throughout completion of the study and through the completion of regular "progress reports " as per

NWCPP policy.

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: 15
Total international sample size (including UK):
Total in European Economic Area:

Further details:
Through contact with local ASD support groups, CAMHS teams across North Wales and Educational Psychologists working across North Wales we aim to recruit a maximum of 15 participants. The sample will be young people aged between 11 and 18 years who have been selected following involvement with services supporting them with anxiety related difficulties.

It is thought that 15 participants would be sufficient. This number is greater than normally expected for an interpretative Phenomenological Analysis (IPA), however due to the fact that sometimes children with ASD may find it difficult to participate in long in depth interviews and for various reasons may struggle to answer questions in great detail, recruiting a larger number may ensure that the quality and depth of data is high.

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.*

It is typical for qualitative research to recruit low numbers in order to facilitate a deep analysis of interviews, it allows researchers to recall individual accounts, and this help reduce the loss of any subtle nuances between them. Typical samples in qualitative research range from one participant up to 30 (per homogenous group). Therefore we aim to recruit up to 15 participants across North Wales, in keeping with typical qualitative studies.

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.

Data will be collected through semistructured interviews and will be analysed following a specific form of thematic analysis known as Interpretive Phenomenological Approach, (IPA). IPA requires small and as far as possible homogeneous samples which provide indepth information on the subject of interest. An IPA aims to explore the particular lived experiences of an individual and therefore focusses on thoughts, feelings and an individuals interpretation of these. Such an approach also places importance on the researchers own interpretation of a participants interpretation of their personal and social world, leading to deeper analysis.

This approach was selected for the depth of the information it can provide, and for the partial structure which allows participants to raise all issues that are relevant to them, without the researcher imposing predetermined categories and expectations. The analysis will be conducted manually, following in part the guidelines of Braun and Clarke (2006) and Smith and Osborn (2008). The themes will be “member checked” (another member of the research team will check the themes and categories) to enhance validation of the results.

References:
Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3, 77101.

Smith, JA and Osborn, M (2008) Interpretative phenomenological analysis. In JA Smith (ed) Qualitative Psychology. London: Sage. (2nd ed)

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	Angela	Brennan
Post	Principal Clinical Psychologist		
Qualifications			
Employer	BCUHB		
Work Address	Denbighshire CAMHS,		
	Camhs Clinic, Grounds of Glan Clwyd Hospital		
	Sarn Lane, Bodelwyddan		
Post Code	LL18 5UJ		
Telephone	01745448670		
Fax			
Mobile			
Work Email	angela.brennan@wales.nhs.uk		

	Title	Forename/Initials	Surname
	Dr	Gemma	Griffith
Post	Post Doctoral researcher		
Qualifications	PHD Psychology MSc Applied Behaviour Analysis BSc PSychology		
Employer	Bangor University		
Work Address	School of Psychology		
	Brigantia BUilding		
	Penrhalt Road		
Post Code	LL57 2AS		
Telephone	01248388067		
Fax			
Mobile			
Work Email	g.m.griffith@bangor.ac.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	Brigantia building, Bangor
Post code	LL7 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
	Miss	Lona	Tudor-Jones
Organisation	NHS R&D manager		
Address	R&D office		
	1st Floor, Holywell Community Hospital		

	Halkyn Road, Holywell
Post Code	CH8 7TZ
Work Email	lona.tudorjones@wales.nhs.uk
Telephone	01352718382
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: 01/06/2013
Planned end date: 01/06/2014
Total duration:
Years: 1 Months: 0 Days: 0

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 approx 5

Does this trial involve countries outside the EU?
○ Yes ◉ No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

☐ 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	5
☐ GP practices in Scotland	
☐ GP practices in Northern Ireland	
☐ Social care organisations	
☐ Phase 1 trial units	
☐ Prison establishments	
☐ Probation areas	
☐ Independent hospitals	
☑ Educational establishments	10
☐ Independent research units	
☐ Other (give details)	
Total UK sites in study:	16

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 the potential legal liability of the sponsor for harm to participants arising from the management of the research. Please see attached sponsorship 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 the potential legal liability of the sponsor for harm to participants arising from the design of the research. Please see attached sponsorship 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)

NHS indemnity scheme applies as some participants will be NHS patients.

Bangor University will meet the potential legal liability of the sponsor for harm to participants arising from the conduct of the research. Please see attached sponsorship letter.

Please enclose a copy of relevant documents.

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 the potential legal liability of the sponsor for harm to participants arising from the management of the research. Please see attached sponsorship 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 the potential legal liability of the sponsor for harm to participants arising from the design of the research. Please see attached sponsorship 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)

NHS indemnity scheme applies as some participants will be NHS patients.

Bangor University will meet the potential legal liability of the sponsor for harm to participants arising from the conduct of the research. Please see attached sponsorship letter.

Please enclose a copy of relevant documents.

PART B: Section 7 - Children

1. Please specify the potential age range of children under 16 who will be included and give reasons for carrying out the research in this age group.

The age range of the participants will be 11-18 years. Inclusion criteria states that participants will have had CAMHS input and therefore this age is thought appropriate. Little is known within the literature about the experiences of this age group in relation to ASD and anxiety which provides further rationale in selecting this age group.

2. Indicate whether any children under 16 will be recruited as controls and give further details.

The design of the project does not include a control condition.

3-2. Please describe the arrangements for seeking informed consent from a person with parental responsibility and/or from children able to give consent for themselves.

Initial contact will be made via a professional that has worked with the individual. They will be asked to opt in so that the lead researcher can send out information and further consent forms in the post to them. Once people have opted in information packs will be sent including a consent form for both children and parents to sign. Once this is returned via stamped addressed envelope the researchers are able to make contact with the family. Upon meeting with family the aims and purpose of the study will be reiterated in order to reaffirm consent at the stage. In addition exclusion criteria will be reiterated in order to ensure inclusion and exclusion criteria have been met.

4. If you intend to provide children under 16 with information about the research and seek their consent or agreement, please outline how this process will vary according to their age and level of understanding.

Information sent to the families will be clearly written and concise ensuring that technical jargon is kept to a minimum. Enclosed will be an outline of the aims of the research with a picture of the lead researcher in order to allow the potential participants to familiarise themselves with the lead researcher prior to meeting. This will reduce further anxiety that may arise when meeting someone new for the first time. (Please see attached documents)A cover letter confirming the date and time of the interview will be sent along with a template anxiety experience diary sheet with instructions on how to complete this.

Copies of written information sheet(s) for parents and children, consent/assent form(s) and any other explanatory material should be enclosed with the application.

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	BCUHB - camhs clinics	Title	Dr
Department name	Glan Clwyd Hospital	First name/ Initials	Angela
Street address	Sarn Lane	Surname	Brennan
Town/city	Bodelwyddan		
Post Code	LL18 5UJ		
Institution name	National Autistic Society	Title	
Department name	Trem Clwyd,	First name/ Initials	Audrey
Street address	Canol Y Dre	Surname	Ostanek
Town/city	Ruthin, Denbighshire		
Post Code	LL15 1QA		
Institution name	Educational Psychology Offices	Title	
Department name	Trem Clwyd	First name/ Initials	Micheal
Street address	Canol y Dre	Surname	Duke
Town/city	Ruthin, Denbighshire		
Post Code	LL15 1QA		
Institution name	Autism Initiaives	Title	ASC Specialist Practitioner
Department name		First name/ Initials	Rebecca
Street address	3 Crown Mews, Off Crown Lane	Surname	Steele
Town/city	Denbigh		
Post Code	LL16 3AA		
Institution name	Createasmile	Title	
Department name	www.createasmile.webs.com	First name/ Initials	
Street address	asd.smiles@yahoo.co.uk	Surname	
Town/city	01745 369905		
Post Code			
Institution name	Jigsaw support group	Title	Miss
Department name	www.jigsawsupport.org	First name/ Initials	Donna
Street address	info@jigsawsupport.org	Surname	Reid
Town/city	07799 848270		
Post Code			

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 Mr Pasquale Kornecki on 22/04/2013 11:13.

Job Title/Post:	trainee clinical psychologist
Organisation:	nwcpp bcuhb
Email:	pspf09@bangor.ac.uk
Signature:	.....
Print Name:	Pasquale Kornecki
Date:	28/02/2013 *(dd/mm/yyyy)*

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.
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.

This section was signed electronically by Mr Hefin Francis on 22/04/2013 14:23.

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 Gemma Griffith on 22/04/2013 14:11.

Job Title/Post:	Research Officer
Organisation:	Bangor university
Email:	g.m.griffith@bangor.ac.uk

Academic supervisor 2

This section was signed electronically by Dr Angela Brennan on 23/04/2013 14:28.

Job Title/Post:	Principal Clinical Psychologist
Organisation:	BCUHB
Email:	angela.brennan@wales.nhs.uk

North Wales Research Ethics Committee – West – Favourable Opinion with Additional Conditions Letter

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

NISCHR RES Gwasanaeth Moeseg Ymchwil | Research Ethics Service

Pwyllgor Moeseg Ymchwil Gogledd Cymru - Y Orllewin
North Wales Research Ethics Committee - West

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk
Website : www.nres.nhs.uk

Mr Pasquale Kornecki
North Wales Clinical Psychology Programme
School of Psychology, Bangor University
43 College Road,
Bangor, Gwynedd
LL572DG pspf09@bangor.ac.uk; paskornecki@googlemail.com

17 May 2013

Dear Mr Kornecki,

Study title:	**A qualitative analysis of the lived experiences of young people with Autism Spectrum Disorder (ASD) and co-morbid anxiety difficulties.**
REC reference:	**13/WA/0146**
IRAS project ID:	**123964**

The Research Ethics Committee reviewed the above application at the meeting held on 16 May 2013. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Coordinator Dr Rossela Roberts, rossela.roberts@wales.nhs.uk

Ethical opinion

Ethical issues raised by the Committee in private discussion, together with responses given by you when invited into the meeting:

Social or scientific value; purpose and need; scientific design and conduct of the study; patient /public representative involvement in study design
The Committee considered whether the objectives, design, methodology, and the conduct of the study are appropriately described in the protocol. The Committee concluded that the research design and the proposed analysis were deemed suitable for answering the research question. No further ethical issues were raised in relation to the scientific value and conduct of the study.

Independent review
The Committee discussed whether the study has been independently peer reviewed and whether the review is in scale of the research and risks involved. The Committee concluded that the review of the project by North Wales Clinical Psychology Programme and the Bangor University School of Psychology Research Ethics and Governance Committee is sufficient evidence of peer-review for this type of project. No further ethical issues were raised regarding the peer-review.

Recruitment arrangements; fair participant selection
The Committee was satisfied that the selection of potential participants has taken into account their clinical care and sufficient details are provided in the protocol and the application form regarding the inclusion and exclusion criteria. The Committee raised no further issues.

Favourable risk benefit ratio; anticipated benefits/risks for research participants
The Committee discussed the anticipated benefits and potential risks to participants and were satisfied that the applicant has suitably identified the risks and benefits and highlighted them in the information given to potential participants. No further ethical issues were raised in relation to the risk/benefit for research participant.

Care and protection of research participants; respect for participants' welfare and dignity; data protection and confidentiality
The Committee discussed the information governance aspects of the study. The Committee discussed where and for how long will data be stored, and clarified who will have access to the data; it was noted that the answer provided in response to question A36 of the application form states that information will be held on home computers. You confirmed that this was ticked in error and all data will be kept on password protected Bangor University computers. No further ethical issues were raised in relation to data protection.

Informed Consent process; adequacy and completeness of Participant Information
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 information is clear as to what the participant consents and there is no inducement or coercion. The Committee agreed that the procedures described in the protocol have been addressed in the Information Sheet but felt that some minor corrections are needed to clarify the referral to the GP. The Committee noted that there is an intention to refer participants back to clinicians who referred them initially, but the GP will not know which of the patients he identified as eligible will have signed up for the project.
The Committee requested that explicit consent to inform the GP should be sought.

Suitability of the applicant and facilities
The Committee discussed the suitability of the applicant and concluded that you are sufficiently qualified and adequately supervised to carry out this research.
The Committee noted that it is proposed to use a room in a GP practice and queried the availability at short notice of such a facility; you clarified that the research team plans to be as flexible as possible and will conduct the interviews at participants' home or school.

General comments/ missing information/ typographical errors/ application errors/ suitability of the study summary
The summary of the study as it appears in section A6-1 of the REC application form was deemed to be an accurate description of the study and suitable for publication on the NRES website.

The Chairman thanked you for attending and gave you an opportunity to ask questions. You did not raise any issues.

On the basis of the information provided, the Committee was satisfied with the following aspects of the research:

- Social or scientific value; purpose and need
- Scientific design and conduct of the study
- Independent review ·
- Recruitment arrangements; fair participant selection
- Favourable risk benefit ratio; anticipated benefits/risks for research participants

- Care and protection of research participants; respect for participants' welfare and dignity; data protection and confidentiality
- Adequacy and completeness of Participant Information
- Suitability of the applicant and facilities Suitability of the study summary

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

- Informed Consent process

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS 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" below).

Conditions of the favourable opinion

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

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

The Committee requested that the following amendments are to be made to the Participant Information Sheet and Consent Form

1. The requirement to inform the GP and other relevant Healthcare professionals should be detailed in the Participant Information Sheet

2. The Consent Form should request explicit consent to inform the GP/ other relevant Healthcare professionals.

3. The amended Participant Information Sheets and Consent Forms need translating and the Welsh language version made available to participants. You may wish to include a clarification that interviews will be conducted in English.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers.
The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System 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 approvals from host organisations
It is 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).

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
REC application (submission 123964/442125/1/920)		22 April 2013
Protocol	2	23 April 2013
Letter of invitation to participant: letter to parents	2	11 April 2013
Letter of invitation to participant: letter for cases closed to CAMHS	2	11 April 2013
Participant Information Sheet: young people aged 11 to 16	2	11 April 2013
Participant Information Sheet: young people aged 16 and over	2	11 April 2013
Other: Participant opt-in form	2	11 April 2013
Other: Confirmation of appointment letter	2	11 April 2013
Consent form	2	11 April 2013
Interview Schedules/Topic Guides IPA interview protocol	2	11 April 2013
Sample Diary/Patient Card anxiety diary	2	11 April 2013
Questionnaire: Space Anxiety Questionnaire for children		
Investigator CV		26 April 2013
Other: Academic supervisor CV		19 November 2012
Evidence of insurance or indemnity	UMAL	09 July 2012

Membership of the Committee

The members of the Ethics 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.

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

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/WA/0146	**Please quote this number on all correspondence**

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

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

Yours sincerely

Rossela Roberts

Mr Derek James Crawford, MBChB, FRCS
Chair

E-mail: 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.*

"After ethical review – guidance for researchers"

Copy: Sponsor: Dr. Charles Leek,
School of Psychology, Bangor University
Adeilad Brigantia, Penrallt Road
Bangor, Gwynedd , LL57 2AS e.c.leek@bangor.ac.uk

Academic Supervisor: Dr Angela Brennan
CAMHS Clinic
Ysbyty Glan Clwyd
Sarn Lane, Bodelwydddan
Rhyl, LL18 5UJ angela.brennan@wales.nhs.uk

Dr Gemma Griffith
School of Psychology, Bangor University
Adeilad Brigantia, Penrallt Road
Bangor, Gwynedd , LL57 2AS g.m.griffith@bangor.ac.uk

R&D Office: Mr Sion Lewis
Clinical Academic Office
Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Bangor, LL57 2PW sion.lewis@wales.nhs.uk

North Wales Research Ethics Committee West

Attendance at Committee meeting on 16 May 2013

Committee Members

Name	*Profession*	*Capacity*	*Present*
Dr. Karen Addy	Clinical Psychologist	Expert	No
Dr. Swapna Alexander	Consultant Physician	Expert	Yes
Ms Valerie Barcoft	Volunteer Worker	Lay +	Yes
Mrs. Kathryn Chester	Research Nurse	Expert	Yes
Dr. Christine Clark	Consultant Obstetrician & Gynaecologist	Expert	Yes
Mr. Derek James Crawford	Consultant Surgeon (Chairman)	Expert	Yes
Mrs. Gwen Dale-Jones	Retired Personal Assistant	Lay +	Yes
Mr. Hywel Lloyd Davies	Solicitor (Alternate Vice-Chairman)	Lay +	No
Ms. Gillian Jones	Student	Lay +	Yes
Dr. Mark Lord	Consultant Pathologist	Expert	No
Dr. Neil McKenzie	Retired Physicist	Lay +	Yes
Dr. Jason Walker	Consultant Anaesthetist	Expert	No
Dr. Philip Wayman White	General Practitioner (Vice-Chairman)	Expert	Yes

Deputy Members

Name	*Profession*	*Capacity*	*Present*
Dr. Michael Cronin	Consultant Paediatrician (deputy to Dr. Clark)	Expert	Yes

Written comments received from

Name	*Profession*	*Capacity*	*Present*
Dr. Jason Walker	Consultant Anaesthetist	Expert	No

In attendance

Name	*Position (or reason for attending)*
Dr. Rossela Roberts	Committee Coordinator

Letter to North Wales Research Ethics Committee- West – Details of Amendments

Pasquale Kornecki
Tanrallt
Wern Avenue
Bagillt
CH6 6BY
Pspf09@bangor.ac.uk

Dr Rossela Roberts
Clinical Governance Officer (R&D/Ethics)
Betsi Cadwaladr University Health Board
Ysbyty Gwynedd Hospital
Bangor,
Gwynedd
LL57 2PW

RE: application reference **13/WA/0146**

Dear Rossela,

I am writing regarding a recent ethical review where amendments to certain documentation were requested.

The Committee requested that the following amendments are to be made to the Participant Information Sheet and Consent Form

1. The requirement to inform the GP and other relevant Healthcare professionals should be detailed in the Participant Information Sheet

2. The Consent Form should request explicit consent to inform the GP/ other relevant Healthcare professionals.

I am writing to inform the committee that I have made the above changes to the relevant documents, which are enclosed with this letter. Once these have been approved I will take the necessary steps to have all documentation translated into Welsh.

Yours Sincerely

Pasquale Kornecki

North Wales Research ethics Committee – West – Acknowledgement of Compliance with Additional Conditions Letter

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

NISCHR RES
Gwasanaeth Moeseg Ymchwil | Research Ethics Service

Pwyllgor Moeseg Ymchwil Gogledd Cymru - Y Orllewin
North Wales Research Ethics Committee - West

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk
Website : www.nres.nhs.uk

Mr Pasquale Kornecki
North Wales Clinical Psychology Programme
School of Psychology, Bangor University
43 College Road,
Bangor, Gwynedd
LL572DG pspf09@bangor.ac.uk; paskornecki@googlemail.com

29 May 2013

Dear Mr Kornecki,

Study title: **A qualitative analysis of the lived experiences of young people with Autism Spectrum Disorder (ASD) and co-morbid anxiety difficulties.**
REC reference: **13/WA/0146**
IRAS project ID: **123964**

Thank you for your letter of 28 May 2013.

I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 17 May 2013.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Covering Letter re: documents in compliance with approval conditions		28 May 2013
Letter of invitation to participant: Parents	3	23 May 2013
Other: Participant opt-in form	3	23 May 2013
Participant Consent Form	3	23 May 2013
Participant Information Sheet: Young people aged 11 to 16	3	23 May 2013
Participant Information Sheet: young people aged 16 and over	3	23 May 2013

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
REC application (submission 123964/442125/1/920)		22 April 2013
Protocol	2	23 April 2013
Letter of invitation to participant: Parents	3	23 May 2013
Letter of invitation to participant: letter for cases closed to CAMHS	2	11 April 2013
Participant Information Sheet: young people aged 11 to 16	3	23 May 2013
Participant Information Sheet: young people aged 16 and over	3	23 May 2013
Other: Participant opt-in form	3	23 May 2013
Other: Confirmation of appointment letter	2	11 April 2013
Consent form	3	23 May 2013
Interview Schedules/Topic Guides IPA interview protocol	2	11 April 2013
Sample Diary/Patient Card anxiety diary	2	11 April 2013
Questionnaire: Space Anxiety Questionnaire for children		
Investigator CV		26 April 2013
Other: Academic supervisor CV		19 November 2012
Evidence of insurance or indemnity	UMAL	09 July 2012
Covering Letter re: documents in compliance with approval conditions		28 May 2013

You should ensure that the sponsor has a copy of the final documentation for the study.

It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/WA/0146	**Please quote this number on all correspondence**

Yours sincerely

Rossela Roberts

Dr Rossela Roberts
Committee Co-ordinator

E-mail: rossela.roberts@wales.nhs.uk

Copy: Sponsor: Dr. Charles Leek,
School of Psychology, Bangor University
Adeilad Brigantia, Penrallt Road
Bangor, Gwynedd , LL57 2AS e.c.leek@bangor.ac.uk

Academic Supervisor: Dr Angela Brennan
CAMHS Clinic
Ysbyty Glan Clwyd
Sarn Lane, Bodelwydddan
Rhyl, LL18 5UJ angela.brennan@wales.nhs.uk

Dr Gemma Griffith
School of Psychology, Bangor University
Adeilad Brigantia, Penrallt Road
Bangor, Gwynedd , LL57 2AS g.m.griffith@bangor.ac.uk

R&D Office: Mr Sion Lewis
Clinical Academic Office
Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Bangor, LL57 2PW sion.lewis@wales.nhs.uk

Research and Development Confirmation

GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board

Panel Arolygu Mewnol Y&D - Y Dwyrain
R&D Internal Review Panel - East

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Chairman/Cadeirydd – Dr Nefyn Williams PhD, FRCGP
Email: wendy.scrase2@wales.nhs.uk
sion.lewis@wales.nhs.uk
Tel/Fax: 01248 384 877

Mr Pasquale Kornecki
Trainee Clinical Psychologist
School of Psychology
Bangor University
Brigantia Building, Penrallt Road
Bangor, LL57 2DG pasquale.kornecki@wales.nhs.uk

21 June 2013

Dear Mr Kornecki

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

Study Title	A qualitative analysis of the lived experiences of young people with Autism Spectrum Disorder (ASD) and co-morbid anxiety difficulties
IRAS reference	123964

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

The Committee 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 received were as follows:

Document:	Version	Date
R&D Form – 123964/459201/14/712	-	30/04/2013
SSI Form – 123964/443442/6/591/190245/270688	-	26/04/2013
R&D Checklist	-	-
SSI Checklist	-	-
Proposal	2	23/04/2013
Participant Information Sheets 11-16 & over + Opt in sheet	3	23/05/2013
Opt in sheet	3	23/05/2013
Parent letter	3	23/05/2013
Consent Form	3	23/05/2013
Appt & Opt in letter - closed cases	2	11/04/2013
Anxiety Diary	2	11/04/2013
Interview protocol	2	11/04/2013
Questionnaire – Spence Scale	-	-
SL5 Favourable opinion with additional conditions 13-WA-0146	-	17/05/2013
SL44 Acknowledgement of compliance with additional conditions 13-WA-0146	-	29/05/2013
Ethics Amendments Letter	-	-
UMAL Insurance Certificate 2012-2013	-	09/07/2013
CV – Dr G Griffiths	-	-
CV – P Kornecki	-	-
CV – Dr A Brennan		

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.
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 wendy.scrase2@wales.nhs.uk or 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, may I take this opportunity to wish you every success with your research.

Yours sincerely,

Dr Nefyn Williams PhD, FRCGP
Associate Director of R&D
Chairman Internal Review Panel

Copy to:

Academic Supervisor 1:	Dr A Brennan CAMHS Clinic Glan Clwyd Hospital Sarn Lane Bodelwyddan LL18 5UJ	angela.brennan@wales.nhs.uk
Academic Supervisor 2:	Dr Gemma Griffith School of Psychology Bangor University Brigantia Building Penrallt Road Bangor LL57 2DG	g.m.griffith@bangor.ac.uk
Sponsor:	Mr Hefin Francis School of Psychology Brigantia Building Bangor, LL7 2AS	h.francis@bangor.ac.uk

Forms

Opt-in Letter to Parents for Closed Cases

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

• PRIFYSGOL CYMRU •
UNIVERSITY OF WALES
BANGOR
1884

Dear Parent/Carer,

Within our team, Dr. Angela Brennan, Principal Clinical Psychologist, and her colleague (Pasquale Kornecki, Clinical Psychologist in Training) are doing a research study to understand the experience of anxiety in young people who have Autism Spectrum Disorder (ASD).

I thought your child may be interested in taking part. Enclosed is an information sheet about the study along with an opt-in form and a stamped addressed envelope. If your child would like to take part, please sign the enclosed form and return it in the envelope. Pasquale will then contact you to provide more information and to arrange to meet your child.

Your child is under no obligation to take part in the study. If they do not want to take part, it will in no way affect their care now or in the future.

Many thanks for considering this.

Yours sincerely

(Enter clinician name here)

Information Sheet for Parents/Carers

Dear Parent / Carer,

Your child has been invited to take part in a study, which has been developed to get a better understanding of what it is like to live with Autism Spectrum Disorder (ASD) and Anxiety. This study is a collaboration between the NHS (Betsi Cadwaladr University Health Board) and Bangor University (Department of Clinical Psychology).

It is hoped the study will improve our understanding of young people with ASD's experience of anxiety and to understand what helps them. The study will focus on thoughts and feelings about anxiety as well as how young people with ASD manage anxiety. This will help professionals to support other people with similar difficulties in the future.

Your child has been identified through professionals working with young people who have ASD or from an Autism related charity. The only information that the research team have regarding your child came from the consent form that you returned to us.

Your child was identified as potentially suitable to take part in the research because they have a diagnosis of Autism Spectrum Disorder and have experienced anxiety related difficulties for which they are receiving or have received support.

If you and/or your child agree to participate, please sign and return the second enclosed consent form. When we receive your form Pasquale (the lead researcher) will contact you and your child to arrange a time/day that suits you for the interview. A letter will be sent to confirm the date and time of the interview. In addition to this your child will be sent a one week diary that encourages them to record any feelings and experiences of anxiety that they may have during this time. They do not have to fill this diary in if they do not want to. The interviewer will collect this on the day of the interview.

The interview can take place in your home, school, local CAMHS clinic or GP surgery. On the agreed day and time, Pasquale will meet with your child (or call your child) to talk for about 25 to 60 minutes (or as long as they like). If your child would prefer to communicate in a different way, which would better suit them, please let us know. Before the interview starts they will be asked to fill in a short questionnaire about their experiences of anxiety.

The interview process will start with a few background questions, such as hobbies and interests and how your child spends their time etc. The interview would then move on to talking about your child's experiences of anxiety. This will include discussing your child's feelings and thoughts about anxiety; how they cope with anxiety and how they felt about the support they received for anxiety. The researcher would also be interested in your child's experiences of having a diagnosis of Autism Spectrum Disorder and how this impacts on their experience of anxiety. The interview will be audio recorded, with you and your child's permission, and is anticipated to last for around 25 minutes to an hour.

The interview will be recorded so that we listen again to what has been said. Everything your child says, and the diary sheets they complete, will be treated confidentially. However, if any information is shared during the interview which suggests someone is at risk of harm, the researcher will discuss this with their supervisor and may share information with others, if it is considered necessary. This will be discussed with the young person and you, as appropriate.

Our written record of your child's interview and completed diary sheets will be made anonymous. We will write down everything your child tells us, and then identify main points and write a summary, together with the information provided by other young people who take part.

This information will be included in Pasquale's doctoral thesis as part of his academic course requirements. The results of the information may also be written up for publication in a scientific journal.

Your child is under no obligation to participate, and they may choose not to. In addition, if they participate but at any point during the study they change their mind, just let us know (no need to tell us why) and they will no longer be involved, and all information collected will be destroyed.

Some of the questions asked in the interview address issues that some people might find sensitive, however there is no obligation to answer. There is the option to minimize discomfort by conducting the interview over the phone or via some other method of communication of your child's choosing. However, if participants do experience distress, they may mention this to Pasquale who will speak with them (and with their permission will speak to you as their parents) and try to resolve the difficulty, or they may contact their health care provider or the National Autistic Society (NAS) who will help participants find services. The NAS Autism Helpline telephone number is 0845 070 4004.

If during the interview it is thought that your child could benefit from further support from anxiety then Pasquale will contact any relevant health care professional involved in your child's care, including their GP.

If you need more information about this study, please contact:

Mr Pasquale Kornecki
North Wales Clinical Psychology Programme (NWCPP) Bangor University
Bangor Gwynedd LL57 2DG
Tel: 01745 448670
Email: pspf09@bangor.ac.uk

Information Sheet for Participants (younger)

Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board

• PRIFYSGOL CYMRU • UNIVERSITY OF WALES BANGOR 1884

Understanding the experience of Anxiety in young people with Autism Spectrum Disorder (ASD)

Participant Information Sheet

Information about the research

About the researcher

This is Mr. Pasquale Kornecki; he is doing some research and would like to ask if you would be involved.

<Insert picture- to be added>

Pasquale is a Trainee Clinical Psychologist studying at Bangor University. This is a three-year course and when he finishes he will be a qualified Clinical Psychologist. He is doing this research as part of his course and would like your help.

What is this research about?

Pasquale is doing research about what it is like to have anxiety as well as having ASD. He would like to find out more by meeting with you and asking some questions about what having anxiety and ASD is like for you.

To do this, he will ask you questions about:

- What it is like to have anxiety
- What it is like to have ASD
- What thoughts you have when you are anxious or worried
- What has helped you cope with anxiety
- How anxiety affects your life and the things you do to help with this.

Why have I been asked to take part?

You have been asked to take part because you have Autism Spectrum Disorder (ASD) and have experienced anxiety.

What will happen?

1. If you would like to take part, please complete the opt-in form, which is in this information pack. This just means you are happy for Pasquale to contact you. There is an envelope included for you to send this form back to Pasquale.
2. When Pasquale receives your form, he will phone you and your parents/carers to arrange a time and place to meet that suits you. Your parents can be with you when you meet with Pasquale if you wish.
3. Pasquale will send you a letter to confirm the date and time of the interview. Attached with this will be a diary sheet for you to fill in. On this diary sheet you can record how anxiety makes your body feel, how it affects your thoughts and certain times of the day when you felt anxious. You can also record the things you did to help with anxiety. This is to be done across a one week period.
4. Pasquale will meet you and ask you some questions. If it is ok he will record the interview with a recorder. Before the interview begins you will be asked to fill in a questionnaire about any feelings of anxiety that you may have. This will be scored by Pasquale after the interview and if there are any concerns he will discuss these with you and if necessary with your parents.

5. Pasquale will listen to the interviews and read the diary sheets you send back to him. He will type out the interviews and put the information on a computer, with a password. He will **not** put your name on this information.

6. The information you give in the interview will be written in a report, your real name will **not** be used in any of the reports so no-one except Pasquale and the research team will know who you are.

7. Whatever you say will not be shared with anyone outside our research team. But, if you tell Pasquale something that makes him worry about your own or someone else's safety, then Pasquale will discuss it with his supervisor and may share information with your parents, to make sure that you are safe. If this happens Pasquale will speak with you first about it.

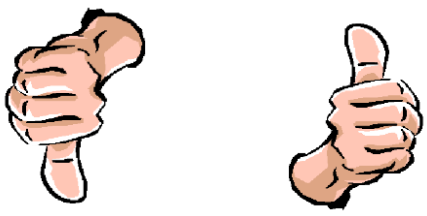
8. If when you meet with Pasquale he feels that you would benefit from some extra help or support with anxiety he will let your health care professional know (this may be your GP).

Do I have to take part?

- If you do not want to meet and talk with Pasquale, just say no.
- If you say yes, but then you change your mind, that is OK too.
- This will not affect any help you get now or in the future.

Would you like to take part in the research?

It is up to you to decide if you would like to take part. You can have some time to think about it and talk to someone you know about it.



What if I have questions about the study?

If you have any questions you can phone or ask someone to phone Pasquale on (enter number here)

Or email

Pspf09@bangor.ac.uk

Complaints or further questions

If you have any complaints or further questions about this research, please contact:

North Wales Clinical Psychology Programme

Bangor University,

College Road,

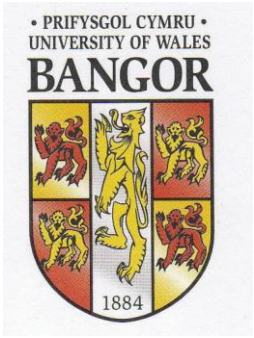
Bangor,

Gwynedd,

LL57 2DG.

Phone number: 01248 382204

Information Sheet for Participants (older)



Understanding the experience of Anxiety in young people with Autism Spectrum Disorder (ASD)

Information sheet for participants

What is this project?
The study we are asking you to take part in has been developed to get a better understanding of what it is like to live with Autism Spectrum Disorder (ASD) and Anxiety. This study is a collaboration between the NHS and Bangor University.

Who will I be talking to?
You will talk to a person called Mr. Pasquale Kornecki. He works for the North Wales Clinical Psychology Programme, Bangor University. He is a trainee Clinical Psychologist and has experience of working with people who have difficulties with anxiety and ASD.

Why is the project being done?
To better understand the experience of anxiety in young people with Autism Spectrum Disorder and what has helped you. This information will help professionals to support other people with similar difficulties in the future.

Why have I been asked to take part?
You have a diagnosis of ASD and have received or are still receiving support for anxiety related difficulties.

Professionals who work with young people with ASD were told about the study and were asked to contact people who they thought might be interested in taking part. This is why they wrote to you. You sent in the form giving consent for us to send you further information about the study. This is why you have received this information pack.

What happens in the study?
If you would like to take part, please sign and return the consent form enclosed. Pasquale will call you to arrange a time, day and place to meet with you. A letter will be sent to you to confirm this along with an anxiety experience diary for you to fill in. The purpose of this diary is for you to record, over a one week period, how anxiety affects your body

and your thoughts. It also asks you to record where you were when you were feeling anxious and what you did to help with these feelings.

You will meet with Pasquale for 25 to 60 minutes (or as long as you like). If you would prefer to communicate in a different way, which would better suit you, please let us know. You will be asked to fill in a short questionnaire about your experiences of anxiety.

What will we talk about?
Pasquale will get some background information and ask a range of questions about your experience of anxiety and what has helped you. The interview will be audio-recorded, with your consent.

What happens with the information you provide?
The information you give will be treated confidentially, unless we are worried about your safety or someone else's. If this happens, Pasquale will discuss it with his supervisor and we may share some information if we consider it necessary to keep you and others safe. If this happens, we will discuss with you what we are doing and why.

The information you give will be made anonymous, so no-one can identify you. The information provided by you and other young people will be included in Pasquale's doctoral thesis as part of his academic course requirements. The results of the information may also be written up for publication in a scientific journal.

What if you do not want to take part?
You do not have to take part. If you want to participate but change your mind, just let us know (no need to tell us why) and you will no longer be involved, and all information collected will be destroyed.

Might something go wrong during the study?
Due to the nature of the topic some people may find some of the questions sensitive. You do not need to answer anything that you do not want to. If anything discussed upsets you, Pasquale will speak to you about this. He may feel that you may benefit from some extra help and support with anxiety and therefore will inform any relevant health care professional involved with you, including your GP.

He may also speak to your parents to try and resolve the difficulty. Your parents may also want to contact their health care provider or the National Autistic Society (NAS) who will help participants find services. The NAS Autism Helpline telephone number is 0845 070 4004.

If you need more information about this study, please contact:

Mr. Pasquale Kornecki
North Wales Clinical Psychology Programme (NWCPP)
Bangor University
Bangor Gwynedd LL57 2DG

Tel: 01745 448670
Email: pspf09@bangor.ac.uk

If you would like to take part .
Please read and sign the consent form in the information pack and return it in the stamped addressed envelope provided as soon as possible.

Thanks for your time!

Complaints/further questions
If you have any questions or concerns about this research, please contact North Wales Clinical Psychology Programme, Bangor University, Bangor, Gwynedd, LL57 DG, Tel: 01248 382205.

Participant Opt-in Form

Understanding the experience of Anxiety in young people with Autism Spectrum Disorder (ASD)

PARTICIPANT OPT-IN FORM

- I have read and understood the information sheet provided
- I am happy for Pasquale to send me an information pack about the study

Pasquale can send information to the following address: _____ _____ _____

Or:
Email address:
_____ ____

Or:

Pasquale can telephone me and my family on this number: _____ ____

Signed _____

Date _____

Parent/Carer (print and sign)_____

Participant Consent Form

Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board

Understanding the experience of Anxiety in young people with Autism Spectrum Disorder (ASD)

PARTICIPANT CONSENT FORM

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

☐ I have read the information sheet provided about the study and have had opportunity to ask questions.

☐ I understand that I do not have to take part if I do not want to and that I can change my mind too without having to give a reason. I know that I can ask for all information I have given to be destroyed if I do not want to continue to take part.

☐ I understand that Pasquale and his supervisor's are the only people that will know any personal details about me and that my name will **not** be included in any report or transcript.

☐ I understand that the information that I provide will be used as part of Pasquale's thesis and may later be published in a scientific journal.

☐ I agree for direct quotes to be used in any publication (without my real name being included).

☐ I agree to the interview being audio recorded.

☐ I understand that if Pasquale is concerned about my anxiety

then he can contact a health care professional involved in my care including my GP.
Please turn over ……

- Pasquale can send information to the following address:
  _____
  _____
- Pasquale can telephone me and my family on this number:
  _____
- The best time to call is _____
- He can also contact me on this email address

  _____

After taking part: (*please tick all of the boxes that apply to you)*

☐ After taking part in the research I would like to receive a £10 voucher to spend at _____(please write name of store here)

☐ I would not like a voucher for taking part but would like a certificate.

☐ I would like to receive feedback about the findings of the study by **telephone** or **through the post** *(Please circle which one you would prefer).*

I would like to take part in Pasquale's research and agree for him to contact me to arrange an interview.

Signed _____

Date _____

Parent/Carer (print and sign)_____

Participant Confirmation of Appointment Letter

Date here

Dear (enter name of child here)

Following my telephone conversation with your parent/carer I am writing to confirm the date and time of the research interview. As agreed the interview will take place:

On: date
At: time
Venue :

As discussed, I have included an anxiety experience dairy for you to fill in. This diary is designed for you to fill it in after you have experienced anxiety. The aim would be to record any experiences of anxiety over a 7-day period and bring it to the interview with you. There are three pages to the diary for each day. At the top you will need to record the date and the time of the anxiety experience. Please fill in as much as you can but do not worry if you leave bits blank.

You do not have to complete the diary if you do not want to. It is OK if you ask your parents, teachers or anybody close to you to help you.

I look forward to meeting you on the (enter date here)

If you need to re-arrange when we meet, please contact me on (enter telephone number and email address here – contact method to be chosen during telephone conversation)

Yours sincerely

Pasquale Kornecki
Clinical Psychologist in Training

Section 6: General Appendix

General Appendix 1: Extract from an Analysed Interview Transcript – Simon aged 17 years

Original	Exploratory Comments	Emerging Themes
R (…) Erm so would you say that you experience anxious feelings sometimes P yeah, a lot R yeah P Yeah I'm an anxious person	Identifies self as an anxious person	**Able to Identify self as an anxious person**
R before we explore a little bit about anxiety I'm just wondering in terms of ASD and anxiety, how do you see those things, do they fit together, are they related or are they separate altogether?		
P erm I would say the ASD helps me cope with anxiety better R right ok	Having ASD helps him to cope with anxiety due to certain ASD traits such as rigidity and preference for structure/routine	**The preference for structure and routine that comes with ASD helps to cope with anxiety**
P erm my mind is quite structured and analytical and quite I like lists R ok	Generating lists is a useful way to cope with anxiety	
P if you have ever been into my room,		

I mean you obviously haven't, there are I've got old exercise books, which are just filled, with lists. They could be about anything shopping lists, lists of what I've got to do, lists of guns I want to buy, lists of like anything. Erm I do all my work at school in lists, you know bullet points, erm and when I'm really anxious I know that the one thing that calms me down is a list.	Routine/rituals to cope – writing lists in exercise books – random topics plus about special interests such as guns – has a calming effect when anxious	**Writing lists helps with anxiety**
R ok		**Recommended techniques such as exercise and socialising not effective**
P if I'm anxious I'll write a list. I don't find like exercise or going for a walk with the dog like they were some of things that we were recommended to do when we're anxious, they said walk your dog or go see your friends or exercise and I don't find that	Generating lists is useful. More traditional recommended ways of coping such as exercising socialising or going for a walk are not as effective	
R right, ok so they weren't...		
P no I just like sitting down and writing a list.		
R and what do you think it is about the exercise of sitting down and writing a list	This works because its done in a formal structured/ routine based way	**Writing lists work to manage anxiety if done in a structured and formal way**
P erm its about, I do it very formally	?? perhaps due to the structure that is part of ASD	

R right P like a kind of ritual R ok P I can't just write a list now, I would have to sit down and get myself a pen. So I find that restful erm the whole getting ready to write the list getting a piece of paper getting two coloured pens one colour for the bullet points one colour for writing R so there's a method to it P yeah, yeah. R every single time P yeah every single time erm, I also find lists very easy to er, I sometimes if I'm stressed I'll write a list of what I'm stressed about or I'm anxious about R right P and then that helps me, it seems less swirling in my head you know in your head when you're anxious, you know if you've	Detailed ritual in order for behaviour to have an effect in calming him down – needs particular equipment Lists of what might be causing stress or anxiety helps – problem solving when "stressed"	**Writing lists helps clarify problems** **Thinking is unclear when anxious**

been anxious like that. All swirling round you can't quite put your finger on it and you'll write a list and you've got "oh I'm anxious about that that that and that".	Thoughts "swirling" in his head when anxious - ?? experience of anxiety – difficult to articulate "put finger on"	**Making lists helps to organise thinking – problem solve**
R ok		
P and you can sometimes think of ways to deal with it. It just helps clarify things	Lists can help with problem solving and get some clarity	
R ok, thank you. When you visited CAMHS did you ever receive any support for anxiety		
P yeah.		
R yes, can you tell me a little bit about that that support and that experience	Group based support,	
P erm I went to I can't remember what the group was called I went to a group at....I'm not going to be able to tell you what it's called	Can't remember what it was called	
R that's ok		
P at some hospital, semi-hospital place down the road from here, a fair way down	Group for anxiety – not autism specific	

the road, erm by the sea. Erm and I used to go there with other people who had similar issues but not autism R right P er, and we used to learn all sorts of techniques so there was like Teflon frying pan where you had to pretend that your thoughts were on a Teflon frying pan and they just slid off, and there was making thoughts into clouds and all sorts of things and I went there for a couple of weeks R ok and you said that there was, the other people in the group didn't necessarily have Autism P no but they had anxiety issues R so they had anxiety; that was what brought people together P and I don't know if you had, do you have any record of what I was ill with R no P I had anorexia	Used cognitive techniques – Teflon frying pan, thoughts into clouds. Quite abstract ?? usefulness compared to concrete behavioural	**Attended group therapy for anorexia – not ASD specific**

R oh right ok P so it was largely to do with, there was a lot of people with eating disorders there. R right P so, coz apparently those two things are quite heavily linked, anxiety and eating disorders. It was to do with eating disorders and anxiety and that was what we did there R how did you find that approach, thinking about metaphors the, the use of things like the Teflon frying pan, how did you find that? P erm I don't mean to sound stubborn but I, I just er it didn't work for me. It was I was I stuck with my lists. I mean I tried them R yeah P but they weren't as effective for me	Previous history of anorexia – the group support was for this – Considers link between anxiety and eating disorders ?? understanding of anxiety Difficulty with using metaphors as an approach to dealing with anxiety – found this after trying them ?? abstract nature of these	**Awareness of relationship between anxiety and other mental health problems** **Found abstract and visual techniques too complex and confusing**

R and any thoughts on why they weren't as effective P erm I think possibly because my mind is quite a hectic place, erm the act of trying to get an organised space in your mind to imagine a Teflon frying pan or a beach where all the problems are pieces of rock. That was quite complicated. R yeah P erm that was an issue. And also as well sometimes I'm quite a hands on person I like just having a piece of paper and a pen and getting it down R so its there in front of you? P yeah. Some of the more physical ones, there was one where you had to walk around the room isn't really practical in somewhere like school or something. You had to walk round the room in a or whenever you got to every corner of the room you had to say something R ok	Didn't work because of hectic mind – difficult to find the space and time. Too complicated - ??needs techniques that bring order and structure Preference for hands on practical coping techniques – despite sometimes being impractical in certain situations	**Prefers physical / behavioural methods of coping such as writing** **Active techniques involving walking to manage anxiety helpful**

P it was that kind of stuff helped more R more practical P yeah I'm more of a hands on person R ok. Thank you. Can I ask when you become anxious are you able to talk to family, friends, about these kinds of things P yeah er I talk to my mum most R yeah P she had er I don't know who she saw she won't see CAMHS obviously whatever the adult equivalent is coz she had some panic attacks. She was quite an anxious person. Erm I don't talk to my dad as much about it, erm I don't talk to friends about it. I talk to my mum sometimes. Erm I've got better at doing that I used to think that I was burdening her with stuff she didn't need but we had a talk about it one day and she said that shed prefer to know R ok P rather than be worrying what was	Talks to mum the most Easier to talk with someone who has had similar experiences with anxiety ?? does this mean you appear less different to them Doesn't talk to father about anxious feelings Used to feel that he was burdening members of his family by talking about his anxiety – got better at opening up after a conversation with his mum ?? perhaps reflects that opening up doesn't come naturally/easy -but can talk to mum	**Easier to talk with similar (parental mental health) difficulties –** **Males don't share feelings – difficult to talk to father** **Talks to mum regularly**

up with me. So I talk to my mum quite regularly about how I'm feeling actually R and are there any particular reasons as to why you don't talk to say friends about these things P erm I only really have two friends R ok P er and as much as I like them neither of them have the patience or you know, we're boys, I may be Autistic but I'm still a boy, you know, lads don't really talk about their feelings R ok P erm I don't talk to my dad probably for the same reason I like you know just you don't talk about your feelings and stuff like that I'm not very good at that yet. R fair enough P erm, and yeah talk to my mum and the CAMHS people but no I don't talk to my friends for that reason mainly because	Only has a small number of friends – and has the belief that "lads" don't share feelings so doesn't seek help from his friends regarding anxiety Recognition that whilst having ASD social rules still apply Preconceived idea that fathers and sons don't share feelings due to their gender – not good at this yet - ?? learning to do this suggests not natural for him	**Limited number of peer relationships** Males don't talk about feelings

there boys R ok. So how often during the day would you say you feel anxious? P I would say there's generally a permanent background anxiety R ok P which is quite low level but it's always there, I'm a nervy person. Another piece of medical information which will play into this is I have a very rare genetic disorder called Ehlers-Danlos syndrome, I injure very easily and my injuries take a very long time to heal so I have always been anxious about being jumped on rough and tumble you know play at school like that. I've had a couple of things where it's ended up with you know in hospital. A) I don't like getting other kids in trouble because you know it's not their fault and B) I don't like having you know my shins ripped up R yeah so you injure more easily P very easily	Able to identify level of anxiety - Permanent background anxiety Physical health condition – Ehlers-Danlos means that he is more susceptible to injury and lengthened recovery time Anxiety linked to worries about health condition – Ehlers Danlos syndrome – injures easily and wounds take a long time to heal Doesn't like the physical problems that occur Doesn't want other kids to accidentally hurt him and then get into trouble for it	**Perception of constant background anxiety** **Physical health condition contributes to anxiety** **Anxious about getting hurt through physical play** **Concern for others** **Increased vigilance of surroundings when in school**

R right		
P I dislocate as well very easily, er so I'm quite generally anxious at school there's big crowds so I'm always watching on the corridors keeping out of the way of people you know checking my back to check that there's not someone running along. Erm but I'm probably anxious about a specific issue maybe four or five times a day	Finds himself checking in school for people behind him in case they might knock into him and exacerbate his physical condition – big crowds are therefore difficult	**Anxiety occurs at various times** **Anxious for discreet periods**
R right ok	Has anxiety up to 5 times a day usually for 15 minutes to 1 hour by which time he has usually worked out what to do – problem solving	
P and it tends to last about, it will last anywhere between 15 minutes to an hour.		
R ok		
P its unusual for me to be anxious for longer than an hour in any concent…, you know in a concentration of anxiety.		**Awareness of how to control anxiety**
R ok		
P usually after an hour I've worked out what to do to calm down	Problem solving to work out how to manage/cope with anxiety	
R and are there does your anxiety follow a specific pattern during the day or		

can it just spring up at any P no it has to have something to spark it so it doesn't just appear R right P erm but other than having something to spark it it can appear wherever. There are a couple of main things that cause it but it can appear any time R and what kinds of things would trigger your anxiety P erm poor grades, erm social faux pas, which I'm sure if you're working with autistic people you'll get a lot of that I'm sure, erm that makes me anxious, I had an incident about a year ago where I made a very large faux pas with a boy at school who used to be my friend and the next day I came in and he beat me up R ok P and since then I've been especially anxious about things like that. Erm so that's a big one especially in school coz	Something has to trigger anxiety for it to start – not random Social faux pas – messing up in social situations where he will offend or insult someone inadvertently Perception that social faux pas are common in those with ASD Poor grades causes anxiety - ?? high standards/expectations	**Mistakes in social interaction cause anxiety** Will inadvertently offend others **Ongoing anxiety following social failure**

you're interacting with people all the time. Erm poor grades, social faux pas, and sometimes with my hobby being guns and shooting, sometimes I can become quite anxious about not being able to get a license for a gun R right P or worrying that I have done something to jeopardise my chances of applying for a gun or something along those lines. An example today would be, I still go out shooting quite a bit but I just use other peoples guns coz I can't have one coz of my illness erm I've got a little gutting knife for rabbits and stuff and it was in my school bag today by accident, I didn't get it out in school mum found it and that sent me into an absolute spiral of panic coz you know I thought she'd think I'm going to stab someone at school or I'm you know dealing drugs coz I'm carrying a knife, it was just an accident R ok, what if we could just explore that a little bit so you're mum found the knife P yeah	The thought that he won't be able to get a licence for his gun, something that he would need in order to pursue his hobby in the future?? disappointment Predicting the thoughts actions of others • Mum found a hunting knife in his school bag accidentally left there from when he was showing it to his friend – led him to start to panic "spiral" (suggests severe and out of control) and predict what his mum might be thinking – thinking the worst about him	**Worrying about future opportunities** **Catastrophic thinking about everyday mistakes/accidents** **Predicting/assuming what others think about you causes anxiety**

R and then what happened P erm, I sat down explained exactly what happened, a friend had been round yesterday, we'd been mucking about with my knives coz you know I've got two or three, that I use for different things, and erm id wanted him to stop when he went out to go get a drink, I just put them in my bag, just slid them R out of the way P yeah and I'd forgotten about it and I'd gone into school and it was there in my bag and I thought oh shit I'm going to get in big trouble here erm, and id come home and it had fallen out of my bag in the car and me having to explain that that was how it had happened and how I wasn't you know carrying them round to kill people or whatever, and I'm still anxious now residually from it I mean I know my mum my mum trysts me she knows I'm a law abiding person and it would be against the law to carry around a knife that large, she knows I'm law abiding she knows that I'm telling the truth but it's still residually the	Even though he knows/ believes his mum considers him to be trust worthy he still finds himself doubting things which causes anxiety – is she noting down and recording his behaviour – awareness of residual anxiety after the event had taken place	**Catastrophic thinking about an accidental event leads to anxiety** **Awareness of residual anxiety following event with mum**

issue about anxiety is what if she doesn't believe me what if she's noting this down R ok, and where do, what did you notice yourself thinking, P erm I kind of go into third person a bit, it doesn't feel real R ok P when I'm very anxious it just feels like I'm watching a video game or a film, it doesn't feel real. So when I saw it on the floor of the car it had fallen out so I thought oh this isn't happening R yeah P it's like a dream or a nightmare this is not real. She said J***** we need to have a talk. She obviously assumed the worst. Erm and then I start to sweat profusely I get very hot erm I start to shake and my head is just a muddle R yeah P I, I struggle to form, I'm usually quite	When anxious enters third person – observing self – feeling of out of reality – like watching a video/game • Assuming mum would be thinking the worst causes anxiety Physical symptoms include: Sweating profusely Gets hot Starts to shake Difficulty forming words/sentences to usual standard	**Experience of dissociation "not real" when anxious** **Predicting/assuming what others think about you causes anxiety** **Sweating when anxious** **Shaking when anxious** **When anxious forming sentences is more difficult**

eloquent that is something my teachers note in my reports and stuff and I just go to I go to rat shit and just go ah ba bab ba R so it's difficult just to form P I can't form a sentence can't use the kinds of words id usually use erm and then I calm down, I do something to calm down something small and I'll try to write a list R so what would a what would a P today it was I er got in and I organised my pens just very small just put them in order. Erm and that was just enough to let me form my words again you know it was like a stop gap measure and then I explained to my mum and she was absolutely fine with it. And now its fine I've just got probably its more physiological just adrenaline still kicking around a bit R yeah. You mentioned erm social faux pas, P yeah R you said, you said erm social faux	Will do smaller tasks when feeling anxious to regain calmness Employs different coping strategies depending on level of anxiety. Sometimes organising stationary is enough to prevent anxiety from escalating Increased adrenalin	**Breaks down tasks when anxious** **Smaller tasks used for lower levels of anxiety** **Increased Biochemical response when anxious**

pas erm something to do with kind of guns, jeopardising your chance of P getting a gun licences R and poor grades P yeah R so I'm wondering if we can think of this social faux pas, what is it about making a social faux pas that makes you anxious, what causes the anxiety P after the incident with the boy that beat me up its largely physical R ok P I didn't expect that, I didn't think that boy had it in him. R right P I genuinely didn't. He's quite a you know, thinks of himself as a bit of a Hunter S Thompson-esque character you know he's a bit counter culture but he's not violent, I've never seen him be involved in a fight in	Mainly because he didn't expect it from him - ?? doesn't understand the boys actions	Unexpected events cause anxiety

my life and that made me realise you know kind of how anyone can be quite pissed off and get violent erm again my weakness physically and my skin condition exacerbate my fear. Er so that's an issue, another issue is I kind of tend to treat interacting with people as a bit of a game to try and improve my chances of doing well	Social interaction is a game, behaving as if it's a game with rules increases success as he has difficulties interacting socially normally ?? to account for the inherent difficulties with social interaction	Social interaction is like a game
R ok	Feels like a failure if things don't go as expected "wasted effort"	**Feels like a failure when social interaction doesn't go as expected**
P I like my video games I like zoning out with them, and I try and treat it a bit like a video game, you know oh right this persons here there interests are, we have to talk about that with them we have to do this we have to smile at this point and nod at this point and kind of guide myself through it. So part of me just feels like I've let myself down because I try hard at school generally to interact well with people and when I don't do I'm like oh bugger that was a lot of wasted effort. Erm some of it is you know its secondary school you have to have people to interact with and be if not friends with you know matey acquaintances you know someone you can eat your lunch with, not necessarily go and see at the weekend but you can go and sit next to in class. And	Friends are required in secondary school to eat lunch with and sit next to in class Thinking that his friends/acquaintances are dwindling due to his behaviour can trigger anxiety Recognises the "need" for friends and acquaintances in order to make situations like school easier	**Certain relationships provide function within school** **Needs certain amount of friends/acquaintances to survive school**

that number has been dwindling slowly but surely, erm so I'm anxious to keep it at a reasonable level that I've got always in a class someone who I can sit next to or be at least on speaking terms or on not awkward speaking terms with R what would it mean if you didn't have that in a class P erm would mean that I'd failed that I hadn't achieved my goal because I've got a goal to keep a couple of people speaking to. It would make lessons more difficult because I'm at E***** and they've got a big thing about group work there constantly getting us to work in groups, so it would make that very difficult, and also just generally its easier, you can pay less attention if you interacting with someone who you are on reasonably good terms with you know if your with a complete stranger or someone who doesn't like you, you have to really watch your footing checking that your saying the right things, if I'm with someone who's on reasonably good terms with me then I can if I make an accident I go "sorry, sorry tired"	He has a number of goals one of which is to keep a number of people whom he can talk to in class. Feels like he has failed if this does not happen Social interaction is easier when its with someone you know as you can pay less attention to your actions. If its with someone you don't know then this increases the difficulty as you have to spend more time and effort checking what you are doing and what you are saying – would have to make excuses Self monitoring – Seeking verbal and non verbal reassurances	**Friends make lessons easier** **Have to pay attention to the rules of social interaction when around strangers** Increased awareness of self when around others

R ok, so if you're not familiar with somebody what do you find yourself doing P I have to be really on my toes R right P really on my toes checking what I'm saying checking that there, I'm responding right, their responding right you know, erm really watching their facial expressions. I'm familiar with peoples facial expression R ok P I found that I do anyway, like I can read my mum and dad's face very well I can read my sisters face reasonably well, I can't read the faces of kids in my class. But if I'm on reasonably good terms with someone I kind of get the broad gist of what they're feeling. With other people their just enigmatic R and if you can't, if you find yourself in a position where you can't read the face of somebody who maybe you have to interact with or you, what kind of feelings does that bring up	?? effortful again suggestive of it not being natural here Good at reading facial expressions to infer the other persons feelings during interaction – more so with familiar people When he finds that he cannot read a persons facial expressions during an interaction he becomes anxious Recognition that this is out of proportion to situation and likely consequence	**Easier to interact with familiar people** **Emotions can be out of proportion to event**

P erm really sillily out of proportional fear R right P It's like I'm being like mugged or something, it's really big heart pounding ah crap, and I know there's no major repercussion the worst that will happen is I'll say something and they'll go god he was a bit weird but and I know that intellectually but my head is just going "oh god oh god". R so there's a split a divide between what you know intellectually P yeah and what you feel, yeah yeah. I know nothing's going to happen I know there not going to cause a scene or beat me up or refuse to ever speak to me again, but like my stomach is going "oh god", and I start shaking and stuff. Yeah	Awareness of divide between intellectual understand of a situation and a more physical/emotional understanding of the situation. – the physical/emotional side is more influential in determining how you end up responding	**There is a difference between what you feel and what you intellectually know**

General appendix 2: Extract from Master Theme Table

Main Theme	Sub-themes	Clusters of Emerging Themes
Factors contributing to anxiety	• ASD-related – rules/morality/accuracy and preference for routines	• Should not be late • Things being unfair causes anxiety • Gender roles • Anger when given false information • Plans/routines help with anxiety • Routines/plans disrupted causes difficulties • Routines can be adapted if needed • Insistence for routines
	• Triggers/incidents (including being bullied)	• Triggers relating to routines/plans • Environmental triggers • Triggers relating to peers • Media influences • Certain responsibilities in the family • Understanding and memory difficulties • Being alone/independence • Sensitivity to noise • Other emotions causing anxiety • Actual reported causes/origins • School/academic high standards • Doing/going to new places/things

	• Anxious thinking (including excessive worry over future and responsibility)	• Not happy with how school responds to this • Bullied when younger • Perceptions why bullied • Thoughts around safety/contamination • Anxious thoughts related to being around others • Misinterpretation/catastrophic thinking • Thoughts about physical symptoms • Thinking related more to specific type of anxiety • Thinking something is illogical or you can't explain it • Thoughts linked to previous event • Vicious circle • Thinking about/predicting the future • Has routines/plan to ensure future • Needs to visualise future to stop anxiety • Visualising sometimes makes things worse • Worried about how the future will end up • Worry about future impact of

		actions now • Worrying about future wellbeing of family • Worries about future independence • Relating to others • Worry previous difficulties returning • Worries/responsible for wellbeing of family • Worried about future responsibilities • Worry over parental finances • Responsible for causing arguments in family • Feeling responsible for helping classmates • Change/taking on another role within the family

General Appendix 3: Summary Table of Studies Reviewed

Authors and date	Participant demographics	Outline of methodology	Main findings	Strengths	Limitations
Celik, Yolga Tahrioglu, Firat & Avci (2011)	N=1 Adolescent male with Asperger's Diagnosis Aged 15 Opportunistic sampling through an outpatient clinic	Single Case design. Trial of Aripriprozole administered 5mg daily titrated to 10mg after 14 days. Y-BOCS administered pre and post treatment.	Compulsion and Obsession scores significantly decreased following 3 weeks of Aripriprozole. Initially Compulsion score, 14 Obsession score 17. After 3 weeks Compulsion score 7, Obsession score 6. In addition Social reciprocity improved with eye contact mildly improved.	Comparisons made to other drug treatment (SSRIs) that are effective in managing such behaviours in those with ASD as well as OCD. Comprehensive assessment including use of standardised measures and psychiatric interview. Attempts to make links with biochemical theory, which supports other research. Study aims clearly identified.	Due to lack of a control group and statistical analysis, difficult to fully assume medication solely caused the change in Y-BOCS scores. Although obsessions and compulsions decreased, guilt associated with them remained after 3 weeks – no treatment for mood. No follow-up reported. Single case lacks control comparison and results therefore lack generalisability. C-YBOCS was not used.
Deramus (2009)	N=61 Aged 7-17 years Parent report only Children diagnosed with ASD (autism, Asperger's or PDD-NOS) or OCD	Investigating the difference between repetitive behaviours in ASD and OCD. Parents completed a telephone interview where the OCD portion of the ADIS, SCQ	57.1% of ASD had clinically significant levels of obsessive compulsive behaviour (CY-BOCS). 39.6% had clinical levels of anxiety (SCAS-P). Severity of compulsions,	Good reporting of attrition data and analysis of completer vs non-completer. Reports psychometric data for all	OCD group sample significantly smaller than ASD. Only OCD specific parts of the ADIS administered, therefore symptoms

	Male and female ASD group recruited through the Alabama Autism Spectrum Disorders research clinic and the University of North Carolina. OCD group recruited through local services specialising in OCD	(although this does not seem to be mentioned anywhere in the study) and the SIB-R were administered. Following this, parents completed a battery of questionnaires including; the CY-BOCS, RBS-R, SCAS-P, SRS. These were either completed on paper or over the internet. Means calculated for scores on the CY-BOCS and RBS-R. Composite scores derived combining CY-BOCS total severity with RBS-R total severity. Means calculated for total scores on the SCAS-P and SRS. Mediation analysis to establish relationship between social problems, anxiety and repetitive behaviour. MANCOVA to analyse differences between groups.	obsessions (CY-BOCS), SIB, compulsive behaviour, ritualistic behaviour and sameness behaviour (RBS-R) are the same for ASD and OCD. ASD endorsed more symptoms associated with stereotyped behaviour and restricted behaviour. OCD had significantly more obsessions, ASD had more severe and more stereotyped and restricted behaviours.	assessments used.	may be better explained by other anxiety disorders, than OCD. Data reported by parents, may have limited the accuracy.
Ivarsson & Melin (2008)	N=109 Children and adolescents Primary OCD diagnosis according to DSM-IV Predominantly Swedish Recruited from a specialised OCD unit	Prevalence and symptoms of ASD in OCD. Questionnaire based. Measures used: The Kiddie Schedule for Affective Disorders and Schizophrenia-Present State and Lifetime Version (KSADS-PL), CY-BOCS, Autism Screening Questionnaire (ASQ), High Functioning Autism Spectrum Screening Questionnaire (ASSQ). T-Test and chi-square. Appropriate steps taken to	ASD traits common in OCD, however ASD traits also associated with co-morbid problems such as tics/Tourettes and ADHD. No relationship between OCD patient's insight into meaningless or excessive nature of symptoms and the ASD traits assessed by the ASSQ. Severity OCD did not affect ASSQ scores. Pathological doubt strongly	Clear attrition data recorded. Replicates previous findings with other child studies of prevalence rates of ASD traits in OCD.	Parental reports depend on parental interpretations and miss out on the subjective experience of internalised states. Perhaps better to use a more comprehensive assessment such as the DISCO.

		manipulate ANOVA due to data not being normally distributed.	predicted ASSQ.		
Lehmkuhl, Storch, Bodfish & Geffken (2008)	N=1 12 year old male with autism and OCD Average IQ Support received from SALT, OT and physical therapy	Single case design. Intervention based on the model proposed by March & Mulle (1998). Seen for 10, 50 minute CBT sessions over a 16 week period. Adapted accordingly for developmental level. Cognitive restructuring and imagined exposure suspended due to difficulty identifying obsessions, thus cognitive component was coping statements and identifying feelings of distress. ERP began 2 sessions earlier than previously thought. Parent and teacher involvement. Behaviour reward system implemented to minimise challenging behaviour and improve adherence to homework. CY-BOCS pre and post used as outcome measure.	Pre and post data using the CY-BOCS – Significant decrease. Pre treatment (18, moderately severe), post treatment (3, well within normal limits). Maintained at 3 month follow-up. Suggests CBT effective in treating OCD in ASD, with appropriate modifications.	Adds to the emerging literature of the efficacy of CBT for children with ASD + OCD.	No formal assessments used to assess OCD. Lack of comparison and small sample size therefore difficult to attribute change solely to treatment. Single case design means findings may not be generaliseable. The intensive early intervention he received meant he exhibited fewer symptoms of autism than is common, therefore he may not be representative of children with ASD at that age.
Lewin, Wood, Gunderson, Murphy & Storch (2011)	N=70 Aged 7-13 years 74% of participants were Caucasian IQ above 70 Recruited from 2 sites, with expertise in the assessment and treatment of paediatric OCD and ASD; The University of	Investigating co-morbid ASD and OCD in children. Participants administered a battery of tests; interview schedule for children and parents – 4th edition, ADIR, ADOS, CY-BOCS. Chi-squared and t-tests to examine group differences. Risk ratios. Discriminate functional	No difference in OCD symptom severity between the two groups, either total, obsessions or compulsions. ASD + OCD less sexual obsessions, checking, washing or repeating compulsions than OCD. ASD + OCD no more likely to endorse hoarding, repeating and ordering, than	Rater training implemented using observation and video tape and live administration, as well as supervision.	A control group of ASD without OCD was not available. Functional impairment data was not available. Relatively small sample size increases probability of type 2

	South Florida and the University of California	analysis.	OCD. Classic/common obsessive-compulsive symptoms less common in ASD + OCD.		error.
Mack, Fullana, Russell, Mataix-cols & Nakatani-heyman (2010)	N=36 Aged 9-18 years Average IQ 3 groups; ASD + OCD, OCD, OCD + Tourettes Retrospectively sampled from specialised OCD service at Maudsley, between 1996-2006	Case controlled study. Treatment group with 2 comparison groups which were gender matched. Compared OCD symptoms across the 3 groups. Assessments used were; CY-BOCS, Children's Obsessive Compulsive Inventory (CHOCI), SDQ. Frequency of obsessions and compulsions compared using Fisher Exact Test. Effect sizes calculated, as well as one way ANOVA to compare across the three groups.	No differences between the 3 groups on frequency of obsessions on the CY-BOCS. ASD + OCD had fewer somatic obsessions and OCD + TS had more sexual obsessions. ASD + OCD fewer games/superstitious compulsions. No difference between groups on total severity. No difference between groups on time spent, interference, distress or resistance associated with obsessions and compulsions.	Attempts made to differentiate between compulsions and autistic rituals by experienced clinicians following interview and review of developmental history. Compulsions were distressing, ego-dystonic and linked to anxiety, autistic rituals were pleasurable and rewarding.	IQ data only available for 5 of the 12 treatment group participants. Small sample size, therefore analysis may be under-powered to detect difference. ASD diagnosis unstructured. No treatment outcome data, therefore differences across the 3 groups cannot be commented on.
Nadeau, Arnold, Storch & Lewin (2014)	N=1 9 year old male with Autistic disorder and OCD (moderate severity) FSIQ of 86	Single case design. 16 family sessions over 21 weeks using family based CBT/ERP (the behavioural intervention for anxiety in children with ASD (BIACA) – modular. 35-70 minutes in duration across 4 months. Assessments used; ADIR, CYBOCS, SRS, ADIS-IV (p/c), MASC, CBCL, CGI-S, WASI.	CY-BOCS reduced from 27 to 0 post treatment. OCD considered to be in remission due to ADIS score being subthreshold (3). CBCL scores within normal range (76 to 64). Decreased parent anxiety 73 to 55 (MASC-P). Social phobia in remission. Specific phobia remained. Some improvements in ASD symptoms – primarily social responsiveness, social communication and	Flexible and appropriate use of modularised treatment. Therapists received regular supervision to ensure fidelity. Addresses various barriers to care.	Lacks generalisability due to single case design. Does not show effectiveness in those with clinically significant mood problems as well – therefore unclear as to what modifications will be needed there.

			awareness.		
Rice (2009)	N=82 American Male and female Adults and children 3 groups; OCD, ASD and ASD +OCD Recruited from a diagnostic and treatment centre in North Eastern USA	Development and validation of a new tool to measure the function of repetitive behaviour (pleasure-seeking/risk avoidance, soothing/distressing, internalised/intrusive, metaphoric/concrete and adaptive/disruptive). Client and informant self-report measure. ANOVA to compare scores across groups. Exploratory factor analysis was conducted to derive the final set of sub-scales	4 factors emerged demonstrating reasonable consistency across three types of informants; intrusive, soothing, level of distress and pleasure seeking. Individual's perceptions of intrusiveness of their RB strongly correlated with their parent's perception. Correlations for the remaining scales across informants were typically low. Compulsions in OCD more intrusive than the pre-occupations and stereotypies ASD. ASD reported more pleasure seeking And soothing qualities in their behaviour.	Tool constructed in collaboration with individuals with ASD and/or OCD. Established validity for the tool. Clear consideration of risks and benefits to participants.	CY-BOCS not used for younger age group. The statistical model EFA requires a larger sample size. Diagnostic tools not used, diagnostic certainty cannot be established and true overlap may be higher than reported.
Ruta, Mugno, GenitoriD'Arrigo, Vitiello & Mazzone (2010)	N=60 Aged 8-15 years Average IQ 3 groups, OCD, Asperger's and healthy controls Recruitment via mental health professional and school counselling and mainstream school for the control group	Presence of OCD traits in ASD. OCD group – Kiddie Schedule for Affective Disorders and Schizophrenia-Present and Lifetime Version (KSADS-PL) used to confirm OCD diagnosis. AS group – the ADIR, the ADOS and the ASDI used. All participants administered the CY-BOCS. Children and parents directly interviewed and all children observed by the principal investigator. Chi-squared, Fisher Exact test and one-way ANOVA.	AS higher frequencies of saving/hoarding obsessions and repeating, ordering and hoarding compulsions. OCD higher frequencies in contamination and aggressive obsessions and checking compulsions. Severity of OC symptoms significantly higher, in the OCD and AS groups. In contrast no differences found between AS and OCD on degree of ego-dystonicity.	Inter-rater reliability assessed through independent blind interviewer (kappa = 0.91).	CY-BOCS not specifically designed for children with ASD, therefore may have found it difficult to explain some of their OC symptoms in the interview. Small sample size reduces power to detect statistical difference.

Sasayama, Sugiyama, Imai, Hayashida, Harada & Amino (2009)	N=1 15-year-old female with severe OCD and Asperger's Several previous medication trials were not effective in reducing symptoms Hospital inpatient	Single case design. Paroxetine started concurrently with behavioral therapy, dose was titrated to 60 mg/day (reduced in the third month to 40mg/day due to irritability and sweating). 6 month treatment. Y-BOCS used as an outcome measure.	Y-BOCS score reduced from 40 to 14. Whilst contamination fears and compulsions related to OCD diminished, obsessive traits associated with PDD (prior to onset of OCD) remained.		Y-BOCS and not CY-BOCS used. Concurrent behaviour therapy limits the evaluation of paroxetine alone.
Scahill, McDougle, Willimas, Dimitropoulos, Aman, McCracken, Tierney, Arnold, Cronin, Grados, Ghuman, Koenig, Lam, McGough, Posey, Ritz, Swiezy & Vitiello (2006)	N=172 Aged 5-17 years Males and females Diagnosed with either AD, AS or PDD-NOS All medication free Participants enrolled in one of two RCT's; a controlled trial of Risperidone, in children with autism, accompanied by aggression and a controlled trial of Methylphenidate in children with PDD and hyperactivity	Development and validation of CY-BOCS-PDD. The CY-BOCS was modified for use in children with PDD. Obsessions checklist and severity scales were dropped. Compulsions checklist was retained and expanded to include repetitive behaviours commonly seen in children with PDD. In addition compulsion severity items were altered to allow for parent report. The CY-BOCS PDD interview was administered to primary caretakers at baseline. Additional assessments administered: ABERRANT Behaviour Checklist (ABC), ADIR, CSI, Vineland adaptive behaviour scale, WISC-III. Correlations and Cronbach. Exploratory analysis. Compared reliability and validity of the CY-BOCS PDD in those with IQ above 70 and below 70.	Reliability – 0.97 indicated excellent reliability across raters (inter-rater). Chronbach's alpha of 0.85 suggested high internal consistency for the 5 severity items. Validity – Low correlation with other measures of repetitive behaviour (ADIR and ABC). Negative correlation between Vineland and CY-BOCS PDD indicates children with better adaptive skills had less severe repetitive behaviour. Exploratory analysis revealed no significant difference between the 3 item or the 5 item scale (time spent, distress, interference, resistance and control). Sensitivity to change – in the Risperidone trial, the 5 item CY-BOCS demonstrated sensitivity to change.	Investigators systematically trained to administer the modified CY-BOCS, through live or taped demonstration. Inter-rater reliability established. Multi-informant led. Useful measure of change.	Large number of behavioural problems associated with the sample. Used categorical IQ scores as measured by several assessments, therefore unable to evaluate the relationship of IQ and repetitive behaviour as measured by the CY-BOCS PDD. Findings may not generalise to children with less severe problem behaviours or those with repetitive behaviour as a primary problem.

Scahill, Dimitropoulos, McDougle, Aman, Feurer & McCracken et al (2014)	N=291 Male and female Aged 4-17 years ASD diagnosis 72.4% white, 12.5% African American, 7.4% Hispanic, 5.1% Asian and 2.6% other 51.8% classed as intellectually disabled	Component analysis of an assessment with data gathered from multiple sites with children with ASD. ASD diagnosis based on interview and observation and supported using the ADIR. The Children's Yale Brown Obsessive Compulsive Scale was modified for autism spectrum disorder. Principle component analysis used to examine the CY-BOCS checklist. Components were dropped that were endorsed by less than 5%.	A 5 component model (1 – hoarding and ritualistic behaviour, 2 – sensory motor and arranging, 3 – insistence on sameness and self-injurious behaviour, 4 – stereotypy and 5 – restricted interests) yielded the best classification of repetitive behaviour, accounting for 34.4% of the variance. Internal consistency for the 5 item CY-BOCS-ASD total score was 0.81. Several of the original CY-BOCS items irrelevant for ASD.	Raters were trained and video recordings used to illustrate methods for administering the assessment measure.	Sampling methods may not be representative. Repetitive behaviours may have been missed by the expert panel in assessment and therefore may change the factor structure.
Wu, McGuire, Arnold, Lewin, Murphy & Storch (2014)	N=46 Youth with ASD and clinically significant anxiety Aged 7-15 years All scored 8 or higher on the CY-BOCS Currently participating in psychotherapy research studies	Validity of CY-BOCS for youth with ASD and sensitivity to treatment change. Treatment was either CBT or behavioural interventions for anxiety in children with autism (BIACA). Clinicians blinded to treatment condition. Measures at baseline and post-treatment (CY-BOCS, ADIS-IV C/P, child behaviour checklist, MASC-P, social responsiveness scale, parent rated). Independent sample t-test. Internal consistency using cronbach alpha. Intra-class correlation to assess inter-rater reliability. Treatment sensitivity assessed through independent sample t-test.	Reliability: Internal consistency – CY-BOCS total score = good, 0.82 Obsession severity scale = good, 0.86 Compulsion severity scale = poor, 0.59 Interference/distress = adequate, 0.84 Resistance/control = adequate, 0.73. Inter-rater reliability – excellent agreement on CY-BOCS total score across raters. Good/excellent for obsession severity scale and good/excellent for compulsion severity scale. Treatment sensitivity:	Inter-rater reliability of the CY-BOCS was calculated on a sub-set of 20 participants.	Predominantly male Caucasian sample. All participants had significant anxiety difficulty, which may limit the generalisability. Convergent and divergent validity only assessed using parent report measures. CY-BOCS factor structure and test-retest reliability not assessed.

		Treatment effect size using Cohen's D.	treatment associated with a significant reduction in OC symptom severity. Significant reductions in both obsession and compulsion severity at post-treatment. No difference between treatment type.		
Zandt, Prior & Kyrios (2007)	N=54 Mean age of 12 years Children and adolescents 3 groups; ASD, OCD and typically developed No significant difference in IQ across all participants Recruitment through hospitals, via advertisements, through primary schools and families known to the researchers (control group only)	Presence of repetitive behaviour in ASD +OCD. Parents and children decided whether assessments were delivered solely through parents, children or a combination of both. If delivered on an individual basis the other parties were consulted afterwards. Multidisciplinary assessment for ASD. ASD and OCD diagnosis using clinical interview with children and parents, language and cognitive tests. The repetitive behaviour questionnaire (RBQ) and CY-BOCS administered to all participants. Effect sizes reported. Non-parametric tests used due to the data not being normally distributed. ANOVA and t-tests used.	ASD and OCD engage in similar levels of sameness behaviours and repetitive movements. Two clinical groups showed significantly higher levels of repetitive behaviour than the control group. OCD rated higher on routines and rituals. OCD more likely to endorse compulsions on all areas than ASD. OCD endorsed more obsessions than ASD. OCD report more obsessions and compulsions than ASD, who in turn report more than controls.		Standardised diagnostic tools not administered. Different assessment formats (questionnaire and interview) may yield different results. CY-BOCS not diagnostic therefore scores should be interpreted with caution when used on those without an OCD diagnosis. Function of repetitive behaviour not reported on.
Zandt, Prior & Kyrios (2009)	N=54 Mean age of 12 years	Executive functioning in ASD and OCD. Parents and children	ASD group performed more poorly than both OCD and		Standardised diagnostic tools not

	Children and adolescents 3 groups; ASD, OCD and typically developed No significant difference in IQ across all participants Recruitment through hospitals, via advertisements, through primary schools and families known to the researchers (control group only).	decided whether assessments were delivered solely through parents, children or a combination of both. If delivered on an individual basis the other parties were consulted afterwards. Multidisciplinary assessment for ASD. ASD and OCD diagnosis using clinical interview with children and parents, language and cognitive tests. The repetitive behaviour questionnaire (RBQ) and CY-BOCS administered to all participants. Executive functioning measures – verbal fluency task, concept generation task (child version), REY complex figure and the walk don't walk task. BRIEF, which is a parent completed questionnaire about daily life. Effect sizes reported. Non-parametric tests used due to the data not being normally distributed. ANOVA and t-tests used.	control on measures of verbal fluency, both semantic and phonemic. Compared to controls the OCD group significantly performed worse on the walk, don't walk task. OCD and ASD experienced significantly more difficulty than controls on inhibit, shift, emotional control, working memory, planning and organisation scales (found using the BRIEF). On each of these OCD and ASD did not differ from each other.		administered. Different assessment formats (questionnaire and interview) may yield different results. CY-BOCS not diagnostic therefore scores should be interpreted with caution when used on those without an OCD diagnosis.

Word Count Statement

Thesis Component	**Word Count**
Title	13
Thesis Abstract	294
Empirical Paper	6935
Empirical Paper References	680
Literature Review	7253
Literature Review References	1137
Contributions to Theory and Clinical Practice	4927
Contributions to Theory and Clinical Practice references	342
Word count excluding tables, figures, reference lists and appendices	**19,115**
Empirical Paper Appendix 1	74
Empirical Paper Appendix 2	765
Empirical Paper Appendix 3	55
Ethics Appendix	
Opt-in letter to parents for closed cases	147
Information sheet for parents/carers	889
Information sheet for participants (younger)	780
Information sheet for participants (older)	810
Participant opt-in form	72
Participant consent form	352
Participant confirmation of appointment letter	211

General appendix

Extract from an analysed interview transcript (empirical paper)	4713
Extract from master theme table	241
Summary table of studies reviewed	3164
Appendices including figures, tables and reference lists, excluding ethics appendix	**14,536**

Total Word Count	**33,651**