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# **The Lived Experience of a Diagnosis of Asperger Syndrome in Adulthood**

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**Thesis submitted in part fulfilment of the degree of**

**Doctorate of Psychology**

**(DPsych)**

**University of Leicester**

**By**

**Joanna Beckett**

**Department of Psychology**

**December 2017**

## **Declaration**

I can confirm that this thesis and research reported within it is my original work. It was written and submitted in part fulfilment of the degree of Doctorate in Psychology (DPsych). It has not been submitted for any other degree or academic qualification.

Joanna Beckett  
18<sup>th</sup> December 2017

# **Thesis Abstract**

The Lived Experience of a Diagnosis of Asperger Syndrome in adulthood

By

Joanna Beckett

## **Literature Review**

Psychiatric comorbidities are not uncommon in Autism Spectrum Disorder (ASD). The current literature review addresses the prevalence of Anxiety Disorders (AD) in Autism Spectrum Disorder without Learning Disability. The findings from the examination of fifteen papers were unequivocal. The risk of AD in the ASD population is elevated and at levels similar to those of clinically anxious individuals.

## **Service Evaluation**

The service evaluation followed two sets of enquiries about the referral patterns and referrals processes in the Learning Disability Service. Data was collated from the electronic data system and focus groups. Following the evaluation, a new referral form was designed and implemented across the \*\*\* Service.

## **Research Report**

Despite the advancements in early detection of ASD, the number of adults seeking this diagnosis remains relatively high. These individuals' presentation often fits with the behavioural phenotype of Asperger Syndrome (AS). This research sought to provide a better understanding of the experience of a late diagnosis of AS. Seven adults with AS were interviewed. Interpretative Phenomenological Analysis was employed to analyse data. Subsequently, four super-ordinate themes were generated: the struggles of being a misfit, revelation, realisation: making meaning of the self and AS and the value and importance of support. The research findings showed that AS diagnosis served as an explanation of a long lasting difficulties and a catalyst for change. The experience of receiving the AS diagnosis was not limited to a single event; it appeared to be a complex process characterised by different emotional and cognitive shifts.

## **Critical Appraisal**

The Critical Appraisal focuses on the research process from the perspective of the researcher. It illustrates the challenges entrenched in the duality of roles of a clinician and a researcher, methodological limitations of the study as well as recommendations for future research.

## Acknowledgment

First of all, I would like to thank the respondents for sharing their very personal experiences with me and letting me enter their unique worlds. Thank you for your time, your effort and your energy. Thank you for putting your trust in me as a researcher. This project would not have been possible without your involvement. I hope that I did justice to your stories and let your voice to be heard, so that you and others with a diagnosis of Asperger Syndrome are given the opportunity to thrive in the predominantly *neurotypical* world.

I would like to extend my genuine thanks to my supervisor, Dr Noelle Robertson for her patient guidance, encouragement and advice she has provided throughout the entire process. Thank you for your insights and comprehensive feedback. Your passion and commitment to the field are inspiring!

Finally, I would like to thank my husband and my friends for believing in me and *being* with me throughout this three-year journey.

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| <b>Service Evaluation</b>  |               |
| Executive Summary  | 621           |
| Full text (exc. figures, tables and references)                    | 4,647         |
| <b>Research Report</b>   |               |
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## **Addenda**

Transcripts have been submitted separately as an Addendum.

Transcript 1: Monica

Transcript 2: Lukas

Transcript 3: Crystal

Transcript 4: Zara

Transcript 5: Mike

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## **PART ONE: LITERATURE REVIEW**

### **Prevalence of Anxiety in Autism Spectrum Disorder across Lifespan: A Systematic Literature Review**

*The literature review was prepared in line with the Journal of Autism and Developmental Disabilities Guidelines. Guidelines to authors can be found in Appendix A.*

## **Abstract**

Anxiety Disorders (AD) are common concerns in clinical samples of individuals with Autism Spectrum Disorder (ASD). Whilst there is abundant research on AD in children and adolescents with ASD, with and without Learning Disabilities (LD), AD in ASD without LD have received little scrutiny. This review identifies, appraises and synthesises 15 studies examining the prevalence of AD amongst individuals with ASD without LD across their lifespan. The review findings reveal an elevated risk of AD in the ASD population at levels similar to those of clinically anxious individuals. The studies utilised diverse and promising anxiety measures but further development in this area is needed. Recommendations for future research along with clinical implications are explored.

Keywords: Autism Spectrum Disorder, Asperger Syndrome, Anxiety Disorders, Prevalence.

## 1. Introduction

Autism Spectrum Disorder (ASD) are lifelong neurodevelopmental conditions characterised by persistent deficits in social communication, social interactions, and social imagination, and accompanied by restricted, repetitive patterns of behaviour, interests and/or activities (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, DSM-V). The clinical presentation of ASDs is highly heterogeneous and may vary over time; this variability, as well as the severity of the core autistic symptoms, can both exacerbate and be exacerbated by co-existing psychiatric conditions and intellectual disabilities (ID).

A vast body of research suggests that individuals with an ASD are at higher risk of developing secondary psychiatric conditions compared with the neurotypical population, with approximately 65% of adolescents with Asperger Syndrome (AS) affected by a secondary mood or affective disorder (Attwood, 2006). The associations between Asperger Syndrome or High Functioning Autism (HFA) and internalising symptoms of depression, bipolar disorders and anxiety are well documented in the literature (MacNeil *et al.*, 2008; Mukaddes & Fateh, 2010; White *et al.*, 2008). In fact, some symptoms of anxiety can manifest as behaviours that are similar to the core features of ASD, such as repetition, ritual or a need for consistency and predictability (Lopata *et al.*, 2008; Gilberg & Billstedts, 2000), and these can be compounded by the variance of intellectual abilities (Bradely *et al.*, 2004; Matson & Nebel-Schwalm, 2007; Reardon *et al.*, 2015; Weller, Watteyne, et al., 1994; Strang, *et al.*, 2012; APA, 2000; Caplan, *et al.*, 2011, Nelson, 2009; Sukhodolsky *et al.* 2008). However, the nature of the relationship between cognitive abilities and anxiety disorders is yet to be established. There are studies indicating positive (Eussen, *et al.* 2013), negative (White & Roberson-Nay, 2009) correlations as well as – a quadratic rather than a linear relation (van Steensel, *at al.* 2011). With respect to the estimates of anxiety prevalence in ASD, these are often derived from research on ASD population with and without ID or ASD population that is not clearly defined with respect to their intellectual abilities (Mazefksy, *et al.*, 2010; White, *et al.*, 2009). Furthermore, the most recent reviews on this subject focus on children and adolescents only (Kerns, *et al.*, 2017; van Steensel, *et al.* 2011; White, et al. 2009).

Given the complexity of ASD and challenges that adolescents and adults with ASD with psychiatric comorbidities but without ID face when seeking support, it would appear paramount to spur an interest in studies on prevalence of psychiatric problems in ASD population without ID, to highlight their unique needs and, to gain an understanding of how these develop, and how they relate to core features of ASD (Lake, *et al.* 2014, Brugha et al, 2007). Since the severity and trajectory of mental health problems is usually associated with developmental stages, the comorbidities in ASD, including anxiety disorders should be studied across the lifespan (Hedley, 2006; Shrayermman, 2007). This it thought to not only inform diagnostic processes but also emphasise the need to improve service provision and therapeutic interventions in the ASD population.

The primary aim of this review is thus to interrogate published literature investigating the prevalence of anxiety disorders in ASD in children, adolescents and adults. Unlike previous reviews, the present review will include studies on individuals with ASD without ID across lifespan, in order to identify a potential trajectory of anxiety. As differentiation between the anxiety symptoms and core features of autism is evidently difficult, this review will also examine the tools currently deployed to assess anxiety in ASD. The methodological and clinical flaws of past studies, as well as their strengths, will be discussed, and recommendations for further research on the subject in order to inform clinical practice will be outlined.

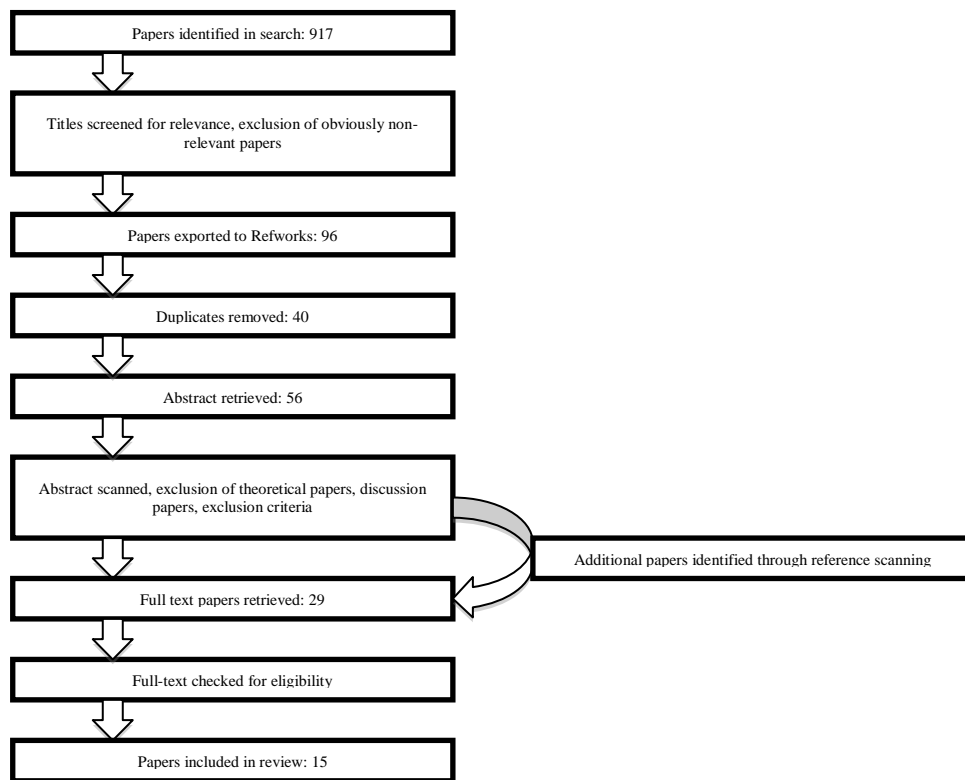
## **2. Method**

### **2.1. Search strategy and study selection**

A systematic literature search of published articles was conducted in January 2016 to identify original, English language, peer-reviewed papers, and repeated in April 2017 to check for newly published articles. Relevant papers were identified using the following online databases: Medline, PsycInfo (incorporating PsycArticle and PsycExtra) and Scopus. The keywords selected for the search included any

combination of the following terms: (1) autism or Asperger(s) and (2) anxiety or anxious, and (3) comorbid or co-occurrence or prevalence.

The search strategy yielded 917 abstracts. The titles were screened for relevance against the inclusion criteria and non-relevant papers were excluded. The remaining 96 papers were exported to RefWorks and duplicates removed. Abstracts were then scanned and the reference sections and citations from identified publications searched for further potentially eligible publications. Seven additional papers were identified using this method. Finally, full text papers were checked for eligibility in line with the inclusion and exclusion criteria. Figure 1 shows an overview of the search and screening process.



**Figure 1. Overview of search and screening process**

A final set of 15 studies were identified and included in this review.



## **2.2. Inclusion and exclusion criteria**

Studies were considered eligible for inclusion if they were: peer-reviewed, written in English and examining individuals diagnosed with Autism Spectrum Disorder without Intellectual Disabilities. Only studies that clearly define the intellectual level of the participants (IQ > 70) were included, and those with mixed samples of ASD and ID were not considered. Papers concerning the prevalence of other psychiatric comorbidities were selected as long as the prevalence of anxiety disorders in ASD was measured and its rate was reported. Papers were required to employ quantitative designs; single case studies and studies concerning the phenomenology of anxiety in ASD as well as other theoretical papers on anxiety and ASD, studies examining the efficacy of interventions targeting anxiety in ASD, studies on general developmental delays and other general reviews were excluded.

## **2.3. Data extraction, appraisal and synthesis**

Key information from each eligible study was extracted and summarised in tabular format (see Table 1). Extracted data included country of origin, study type and design, sample characteristics, selection process, relevant measures, primary findings and limitations. The credibility of the identified studies was evaluated on the basis of the quality of the anxiety instruments applied and methodological rigour of the prevalence studies.

First, the methodological quality of the studies was evaluated according to guidelines set out by Boyle (1998; see Table 2). There is currently no formal recommendation for the application of critical methods in relation to prevalence studies in literature reviews, which explains the great variability in the appraisal tools used for this purpose. The guidelines set out by Boyle (1998) refer specifically to prevalence studies of psychiatric disorders, and these were employed effectively in a previous systematic review of anxiety in the population of children and adolescents with ASD (MacNeil *et al.*, 2009). Thus, sampling, measurement and the suitability of statistical analyses were appraised. More specifically, each study was assessed against the following criteria: (1) clarity of

the sample description; (2) confirmation of autism diagnosis by current authors; (3) current comparison group; (4) matching of the comparison groups; (5) standardised collection methods; (6) reliability of the anxiety instrument; (7) validity of the anxiety instruments; (8) appropriateness of interpretations.

Second, the studies were evaluated in terms of the anxiety assessment methods they utilised (see Table 3), which are of particular significance due to difficulties and ambiguities in differentiation between anxiety and symptoms of ASD. The following indicators were used to guide the evaluation of the assessment methods utilised in each study: (1) use of clinical interview; (2) use of anxiety rating scales; (3) use of direct observation; (4) use of physiological measures; (5) use of multiple informants; and (6) use of methods standardised for the ASD population.

Due to the considerable heterogeneity of the reviewed studies in terms of different methodologies, different methodological robustness and measures applied, a mean prevalence rate of anxiety was not calculated and a narrative approach to synthesis was applied. This was also thought to bring more focus on factors that might have influenced the preliminary synthesis. Since the remit of the present literature review is to identify the rates of anxiety in individuals with ASD across the lifespan, the papers were clustered according to the age stages of the research sample. Due to a high disparity in mean age and the age ranges of participants in the selected studies, it was only possible to assign the papers to two clusters: children and adolescents, and adults. This precluded the making of any comparisons in anxiety levels between children and adolescents. The papers within those two groups were then reviewed in a hierarchical manner, guided by their methodological strength. Thus, the least methodologically robust studies were reviewed first, that is, studies without comparison groups, followed by the studies using normative and community comparison samples, comparisons to other clinical samples and, finally, studies examining differences in anxiety levels across ASD subtypes.

| Author                       | Type of Study & Country  | ASD Sample Age (M)                                       | Control Sample  | Selection Process  | Anxiety Instrument  | Primary Findings  | Limitations   |
|------------------------------|--|--|---|--|---|---|---|
| Bejerot <i>et al.</i> (2014) | Comparison between ASD and SAD and non-ASD<br><br>Sweden         | 50 ASD (30) Range: 27.9 – 32.1                           | 53 Non-ASD (32.2) Range: 28.4 – 32.5<br><br>100 SAD (34.6) Range: 32.8 – 36.4 | ASD: community-based ASD services and ASD website<br><br>Non-ASD: convenience sample<br><br>SAD: newspaper advertisement   | Liebowitz Social Anxiety Scale: self-report   | Significant differences between ASD, SAD and non-ASD<br><br>Higher scores for anxiety and avoidance in SAD compared to ASD and non-ASD<br><br>Higher scores for anxiety and avoidance in ASD compared to non-ASD                    | Small sample sizes<br><br>Assessments conducted at different times  |
| Bellini (2004)               | Measures of anxiety and social skills deficits in ASD<br><br>USA | 41 ASD (14.22) Range: 12 – 18 (19 HFA, 16 AS, 6 PDD-NOS) | No current control group<br><br>Normative samples from instrument manuals     | ASD: Indiana Resource Centre for Autism Database, and Louisiana school   | MASD Scale: self-report<br>BASD Scale: only parent-report part<br>SAS-A Scale: self-report  | Higher levels of anxiety in ASD compared to the mean normative sample on the MASD<br><br>49% of ASD with high social anxiety on the SAS-A<br><br>Higher scores in the ASD on the BASD subscales: Anxiety and Internalising Problems | No current control group<br><br>Sample selection bias: ASD informed of the nature of the study<br><br>Confounding factor: use of medication in 16 cases<br><br>Increased risk of Type I error due to multiple univariate analyses |
| Farrugia & Hudson (2006)     | Comparison between AS, AD and NC<br><br>Australia                | 29 AS (13.76) Range: 12 – 16                             | 34 AD (13.82) Range: 12 - 16<br>30NC (13.90) Range: 12 - 16                   | AS: local support group and the Autism Association of South Wales<br><br>AD: Macquarie University Child and Adolescent Anxiety Clinic<br>NC: newspaper advertisement | The Spence Children's Anxiety Scale (SCAS): self- and parent- report<br><br>The Children's Automatic Thoughts Scale (CATS): self-report | Equivalent levels of anxiety on self-reports in AS and AD<br><br>Higher anxiety symptoms and negative automatic thoughts in AS than NC  | Small AS sample<br>Low response rate in AS<br><br>Possible psychopathologies in NC<br><br>Selection bias: AS informed of the nature of the study  |

|                            |  |  |   |  |  |  |  |
|----------------------------|--|--|---|--|--|--|--|
| Gillott (2001)             | Measures of anxiety and social worries in HFA, SLI and NC<br><br>UK                  | 15 HFA (10.27) Range: 8 - 12                           | 15 SLI (10.25) Range: 8 - 12<br>15 NC (10.26) Range: 8 - 12 | NI   | The Children's Anxiety Scale (SCAS): self-report<br><br>The Social Worries Questionnaire (SWQ): self- and parent- report | Higher rates of anxiety in HFA than SLI and NC<br>7 out of 15 children with HFA at or above clinical mean score  | Small sample sizes<br><br>Groups not matched for IQ<br><br>Possible psychopathologies in HFA, SLI and NC |
| Hofvander (2009)           | Evaluation of psychiatric comorbidity and psychosocial problems in ASD<br><br>Sweden | 122 ASD (29) Range: 16 - 60<br>5 AD, 67 AS, 50 PDD NOS | No controls   | Consecutively recruited adults to the Henri Mondor-Albert Chenevier Hospital in Paris, the Child Neuropsychiatric Clinic in Gothenburg and the Psychiatric Outpatients Clinic in Malmo | The Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)   | Mood disorder (n=65, 53%) as the most common life-time comorbidity, followed by anxiety disorders (n=59, 50%)  | No comparison groups<br><br>Different examinations in Paris and Gothenburg groups                        |
| Joshi <i>et al.</i> (2012) | Evaluation of psychiatric comorbidity in ASD<br><br>USA                              | 63 ASD (29.2) Range: 18 - 63                           | 63 Non-ASD (29.3) Range: 18 - 65                            | ASD: consecutively recruited from ASD programme at a university hospital<br><br>Non-ASD: consecutively recruited from a general psychopharmacology programme at an academic centre     | The Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)   | Higher number of comorbidities in ASD compared to non-ASD<br><br>Higher rates of lifetime major depression and multiple anxiety disorders in ASD (social phobia, agoraphobia, GAD, specific phobia)<br>13.6% of ASD scored above the population mean for generalised anxiety and 8.5% for separation anxiety | Clinically based sample<br><br>No confirmed diagnosis of ASD   |
| Kim <i>et al.</i> (2000)   | Follow-up clinic series.<br><br>Canada   | 59 ASD Range: 9-14<br>19 AS, 40 HFA                    | No current control group                                    | Children from PDD centres contacted for follow up 6 years later  | The Ontario Child Health Study Revised: parent-report  | Higher scores on a measure of GAD and separation anxiety in  | Parent-reports only<br>No current control groups   |

|                                |   |                                       |   |  |   |   |   |
|--------------------------------|---|---------------------------------------|---|--|---|---|---|
|                                |   |                                       | Normative sample from the instrument manual |  |   | ASD compared to the community-based norms<br>No differences in anxiety rates between AS and HFA   | Diagnostic criteria for AS and HFA not based on DSM-IV  |
| Kuusikko <i>et al.</i> (2008)  | Measures of social anxiety symptoms in AS and HFA<br><br>Finland      | 54 AS/HFA (11.2)<br>Range: 8 - 16     | 305 NC (12.2) Range: 8 - 16                 | ASD: Recruited from patient records of Oulu University Hospital in 2003 and an epidemiological study by Mattila <i>et al.</i> in 2007<br><br>NC: randomised cluster sampling selection of children from mainstream schools in Oulu collected in 2006 | SPAI-C: self-report<br>The Social Anxiety Scale for Children (SASD-R): self-report<br><br>The Child Behaviour Checklist (CBCL): parent-report | Older AS/HFA with more symptoms of social anxiety than the community-based sample on all measures<br><br>Significantly higher scores on CBCL in younger AS/HFA than NC<br><br>Significantly higher scores in young AS/HFA than NC on 2 out of 5 SPAI-C factors: Fear of General Conversation and Fear of Public Performance<br><br>No difference between AS and HFA | Different parent- and self-report measures<br><br>Small HFA/AS sample size<br><br>Low participation rate in NC (52.6%)<br><br>NC not screened for autism<br><br>No validation of CBCL on Finnish youth population |
| Lugnegard <i>et al.</i> (2011) | Evaluation of psychiatric comorbidity in AS<br><br>Sweden             | 54 AS (27) range:                     | No control group                            | AS recruited from the Department of Adult Rehabilitation and previous patients at the Neuropsychiatric Clinic for Children and Adolescents   | The Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)  | 56% of AS with at least one AD, 11 of these with two or more ADs<br>22% with social anxiety disorder, 22% with GAD, 15% with agoraphobia, 13% with panic disorder, 7% with OCD  | Clinically-based sample<br><br>Risk of missing individuals who do not request support in adulthood<br><br>Low participation rate: high proportion of non-respondents and refusals                                 |
| Mattila <i>et al.</i> (2010)   | Community- and clinic-based study of psychiatric comorbidities in AS/ | 50 AS/HFA (12.7)<br>Range: 9.8 – 16.3 | No control group                            | AS/HFA from community-based study (2007) – children living in the Northern   | The Schedule for Affective Disorders and Schizophrenia for School-Age Children,   | One or more comorbid psychiatric disorders diagnosed in 74% cases.  | Clinical use of ADI-R and ADOD (not standardised on Finnish population)   |

|                               |   |                            |   |  |  |   |   |
|-------------------------------|---|----------------------------|---|--|--|---|---|
|                               | HFA<br>Finland  |                            |   | Ostrobothnia Hospital District and clinic-based study (2003) – children from schools in Oulu and Oulu University records                       | Present and Lifetime Version (K-SADS-PL): self- and parent-report  | The most common comorbidities: behavioural (44%), anxiety (42%) and tic disorders (26%)   | Recall bias: retrospective assessments on K-SADS-PL<br><br>Confounding factors: parental anxiety  |
| Mukaddes <i>et al.</i> (2009) | Evaluation of psychiatric comorbidities in AS<br><br>Turkey             | 37 AS (10.9) Range: 6 - 20 | No control group  | AS from all individuals referred to a private psychiatry clinic between Dec 2002 and Feb 2007  | The Schedule for Affective Disorders and Schizophrenia for School-Age Children, Present and Lifetime Version (K-SADS-PL): self- and parent- report | 94% of AS with at least one psychiatric comorbidity and 70% with more than one comorbidity<br><br>The most frequent comorbidity: AD (32 % with OCD, 13% with specific phobia, 5.4% with social anxiety disorder, 5.4% with GAD, 5.4% panic disorder, 2.7% with separation anxiety disorder) | Small sample size<br><br>No information on participation rate<br><br>Referral bias: potential overestimation of psychiatric disorders<br><br>Differentiation between OCD and AS symptoms                |
| Park <i>et al.</i> (2012)     | Comparison between AS, ADHD and DD<br><br>Korea                         | 56 AS (9.39) Range: 6 – 13 | 56 DD Range: 6 – 13<br>56 ADHD Range: 6 – 13                                    | AS: from medical records of Psychiatric Outpatient Clinic in Seongnam<br><br>ADHD and DD: random selection from the above clinic               | Child Behaviour Checklist (CBCL): parent-report<br><br>State-Anxiety Inventory (STAI-S)<br><br>Trait-Anxiety Inventory (STAI-T): self-report       | Higher self-reported trait anxiety and parent-reported internalising problems (anxiety and depression) in AS than ADHD and as high as in DD   | Retrospective methodological design: no standardised procedure for arriving at diagnoses<br><br>AS sample recruited on the basis of availability of medical records – not representative for the clinic |
| Russell & Sofronoff (2005)    | Measure of anxiety and social worries in AS, AD and NC<br><br>Australia | 65 AS Range: 10 – 13       | No current control groups<br><br>AD and NC from the normative samples from SCAS | AS from a larger study on the efficacy of anxiety interventions; none with AD – from children’s hospital, psychology clinics and media release | Spence Children’s Anxiety Scale (SCAS): self- and parent-report<br>Social Worries Questionnaire (SWQ): self- and parent-report                     | Higher anxiety scores in AS than NC on self- and parent-reports<br><br>No differences between AS and AD on self-report measures of  | No current comparison group<br><br>All AS received intervention for anxiety   |

|                            |  |   |  |  |  |  |  |
|----------------------------|--|---|--|--|--|--|--|
|                            |  |   |  |  |  | <p>anxiety</p> <p>More social worries in AS and NC in parent ratings, but not child ratings</p> <p>Higher anxiety in AS than AD rated by parents</p> |  |
| Thede & Coolidge (2006)    | <p>Psychological and neurobehavioural comparison of AS and HFA</p> <p>USA</p>                  | <p>16 AS &amp; 15 HFA (10)</p> <p>Range: 5 – 17</p> | <p>No current control group</p> <p>NC from the CPNI normative sample</p> | <p>AS and HFA from registry of the Autism Society of America</p>   | <p>Coolidge Personality and Neuropsychological Inventory (CPNI): parent-report</p> | <p>Higher scores in AS than HFA on scales: GAD, OCD</p> <p>10 out of 16 (63%) AS with elevated GAD scale scores</p>                                  | <p>Small sample size</p> <p>Lack of clinical corroboration of AS/HFA diagnoses</p> |
| Tonge <i>et al.</i> (1999) | <p>Comparison of behavioural and emotional disturbance between AS and HFA</p> <p>Australia</p> | <p>52 AS (9)</p> <p>Range: 4 - 18</p>               | <p>75 HFA (7)</p> <p>Range 4 -18</p>                                     | <p>Consecutive cases presenting for initial diagnosis at Pervasive Developmental Disorder Assessment Service</p> | <p>Developmental Behaviour Checklist (DBC): parent-report</p>                      | <p>Higher scores in AS than HFA on the anxiety scale</p>   | <p>AS older and with higher IQ than HFA</p>  |

**Table 1. Studies examining anxiety in individuals with ASD (IQ>**

### 3. Results

#### 3.1. Overview

An interrogation of 15 papers examining prevalence of anxiety in ASD was undertaken, with the majority of papers examining the prevalence of anxiety in children and adolescents (n=11).

Sample sizes of children and adolescents with ASD ranged from 15 to 254 individuals, aged between 4 and 20 years. All studies on children and adolescents were cross-sectional. Four studies reported on the prevalence of anxiety in adults with ASD. The ASD sample sizes ranged from 50 to 122 adult participants, within the age range of 18 – 63 years.

Of the 15 studies selected for this review, seven included current control groups that consisted of either non-ASD individuals and/or individuals with other clinical diagnoses, such as SAD, AD, SLI, DD, ADHD (Bejerot *et al.*, 2014; Farrugia & Hudson, 2006; Gillott, 2001; Joshi *et al.*, 2013; Kuusikko *et al.*, 2008; Park *et al.*, 2012; Tonge *et al.*, 1999). A further four studies used normative samples from instrument manuals as control groups and the remaining four studies had no control groups (Bellini, 2004; Kim *et al.*, 2000; Russell & Sofronoff, 2005; Thede & Coolidge, 2007 and Hofvander *et al.*, 2009; Lugnegard *et al.*, 2011; Mattila, 2010; Mukaddes, 2009, respectively).



| Authors                                    | The sample is defined clearly | The ASC diagnosis is confirmed by the current author | There is a current comparison group                            | The comparison group is matched                             | The data collection methods are standardised. | The anxiety instruments are reliable | The anxiety instruments are valid | The interpretations are appropriate |
|--|-------------------------------|--|--|---|---|--------------------------------------|-----------------------------------|-------------------------------------|
| Bejerot <i>et al.</i> (2014)               | Y                             | Y  | Y  | Y   | NI  | Y                                    | Y                                 | Y                                   |
| Bellini (2004)                             | Y                             | Y  | N  | N   | N   | Y                                    | Y                                 | Y                                   |
| Farrugia and Hudson (2006)                 | Y                             | Y  | Y  | NI  | Y   | Y                                    | Y                                 | Y                                   |
| Gillott <i>et al.</i> (2001)               | Y                             | Y  | Y  | Y   | N   | Y                                    | Y                                 | Y                                   |
| Hofvander <i>et al.</i> (2009)             | Y                             | Y  | N  | N   | N   | NI                                   | NI                                | Y                                   |
| Joshi <i>et al.</i> (2012)                 | Y                             | Y  | Y  | Y   | Y   | NI                                   | NI                                | Y                                   |
| Kim <i>et al.</i> (2000)                   | Y                             | Y  | N  | Y – within groups of ASD<br>N – no between ASD and non-ASD  | NI  | Y                                    | NI                                | Y                                   |
| Kuusikko <i>et al.</i> (2008)              | Y                             | Y  | Y  | NI  | Y   | Y                                    | Y                                 | Y                                   |
| Lugnegard <i>et al.</i> (2011)             | Y                             | Y  | N  | N   | NI  | NI                                   | NI                                | Y                                   |
| Mattila <i>et al.</i> (2010)               | Y                             | Y  | N  | N   | Y   | Y                                    | Y                                 | Y                                   |
| Mukaddes <i>et al.</i> (2009)              | Y                             | Y  | N  | N   | NI  | Y                                    | Y                                 | Y                                   |
| Park <i>et al.</i> (2013)                  | Y                             | Y  | Y  | Y   | N   | Y                                    | Y                                 | Y                                   |
| Russell and Sofronoff <i>et al.</i> (2004) | Y                             | Y  | N  | NI  | Y   | Y                                    | NI                                | Y                                   |
| Thede and Coolidge (2007)                  | Y                             | Y  | Y - (within ASD groups)<br>N - (within ASD and non-ASD groups) | Y – within ASD groups<br>N – between ASD and non-ASD groups | Y   | Y                                    | Y                                 | Y                                   |
| Tonge <i>et al.</i> (1999)                 | Y                             | Y  | Y  | N   | NI  | Y                                    | Y                                 | Y                                   |

**Table 2. Methodological quality rating system**

(Y – yes; N – no; NI – not indicated)

All the samples were clearly defined and the participants' diagnoses were confirmed by the current authors. Of the 15 studies only one failed to describe the selection process (Gillott, 2001). There was significant variability in the methods used to measure anxiety. Anxiety instruments with good reliability and validity were employed in 10 studies (Bejerot *et al.*, 2014; Bellini, 2004; Farrugia & Hudson, 2006; Gillott, 2001; Kuusikko *et al.*, 2008; Mattila, 2010; Mukaddes, 2009; Park *et al.*, 2012; Thede & Coolidge, 2007; Tonge *et al.*, 1999). There was no indication of validity in two studies (Kim *et al.*, 2000; Russell & Sofronoff, 2005), and the remaining three studies failed to include any information regarding either the validity or reliability of the anxiety measures (Hofvander *et al.*, 2009; Joshi *et al.*, 2013; Lugnegard *et al.*, 2011).

| <b>Authors</b>                 | <b>A clinical interview was conducted</b> | <b>Anxiety rating scales were applied</b> | <b>Direct observation was applied</b> | <b>Physiological assessment measures were used</b> | <b>Multiple informants were used</b> | <b>Comparative data was available for ASD populations for any of the anxiety instruments</b> |
|--------------------------------|---|---|---------------------------------------|--|--------------------------------------|--|
| Bejerot <i>et al.</i> (2014)   | Y   | Y   | Y                                     | N  | N                                    | NI   |
| Bellini (2004)                 | N   | Y   | N                                     | N  | Y                                    | NI   |
| Farrugia and Hudson (2006)     | N   | Y   | N                                     | N  | Y                                    | NI   |
| Gillott <i>et al.</i> (2001)   | N   | Y   | N                                     | N  | Y                                    | NI   |
| Hofvander <i>et al.</i> (2009) | Y   | N   | N                                     | N  | N                                    | NI   |
| Joshi <i>et al.</i> (2012)     | Y   | N   | N                                     | N  | Y                                    | NI   |
| Kim <i>et al.</i> (2000)       | N   | Y   | N                                     | N  | N                                    | NI   |
| Kuisikkko <i>et al.</i> (2008) | N   | Y   | N                                     | N  | Y                                    | NI   |
| Lugnegard <i>et al.</i> (2011) | Y   | N   | N                                     | N  | N                                    | NI   |
| Mattila <i>et al.</i> (2010)   | Y   | N   | N                                     | N  | Y                                    | NI   |
| Mukaddes <i>et al.</i> (2009)  | Y   | N   | N                                     | N  | Y                                    | NI   |
| Park <i>et al.</i> (2013)      | N   | Y   | N                                     | N  | Y                                    | NI   |
| Russell and Sofronoff (2004)   | N   | Y   | N                                     | N  | Y                                    | NI   |
| Thede and Coolidge (2007)      | N   | Y   | N                                     | N  | N                                    | NI   |
| Tonge <i>et al.</i> (1999)     | N   | Y   | N                                     | N  | N                                    | NI   |

**Table 3. . Evaluation of assessment methodology for anxiety**

(Y - yes, N - no, NI - not indicated)

## 3.2. Anxiety in children and adolescents with ASD

### 3.2.1. Anxiety in ASD samples with no comparison group

Two studies explore the rate of psychiatric comorbidities in groups of children and adolescents with ASD, without comparisons to other samples (Mattila, 2010; Mukaddes, 2009). Both studies utilised the same assessment tool, 'The Schedule for Affective Disorders and Schizophrenia for School-Age Children, Present and Lifetime Version', which was not standardised for the population with ASD. Mukadess *et al.* (2009) identified that 20 (54%) of 37 suffered from an anxiety disorder.

In the second study, Mattila *et al.* (2010) report that anxiety disorders (current/lifetime) were diagnosed in 42%/56% of the cases. Furthermore, 14% of participants were diagnosed with two or three different current anxiety disorders.

### 3.2.2. Anxiety in ASD samples compared to normative and community samples

All four studies comparing anxiety rates in ASD samples to normative and community samples suggested a higher level of anxiety among those with ASD (Bellini, 2004; Kim *et al.*, 2000; Thede & Coolidge, 2007; Russell & Sofronoff, 2005). Bellini (2004) reports that adolescents with ASD (n=41) showed higher levels of anxiety compared to the normative sample mean (n=2698) for the Multidimensional Scale for Children (MASD), a self-report anxiety scale. Another tool employed here, the Behaviour Assessment System for Children (BASD), which can collate information received from the child, teachers and parents, was used only to gather data from parents. On the BASD scale, differences between the ASD and the normative sample mean (n=1090) were identified on the subscale for Anxiety, and for a composite domain, Internalising Problems. Scores for a third measure employed in this study, the self-report SAS-A, reveal that almost 49% of the ASD sample was affected by social anxiety. However, normative data for the SAS-A is not established.

In the second study, Kim *et al.* (2000) demonstrates that children with autism and Asperger Syndrome (n=59) report greater rates of anxiety and depression than a standardised community sample (n=1751). They showed that 13.6% of the ASD group scored at least two standard deviations above the population mean on a measure of generalised anxiety and separation anxiety and were classified as 'clinically relevant'. Thede and Coolidge (2007) also report elevated scores on the GAD scale in the AS (n=16) and the HFA samples (n=15), compared to the normative mean (n=780). Similarly, Russell and Sofronoff (2005) report greater anxiety symptoms in the AS sample (n=65) than in the normative sample, for both self- and parent-report measures of the SCAS. They also found that parents' reported social worries were elevated in the AS sample, in comparison with the normative sample.

Bellini's (2004) findings appear consistent with the results of three further studies that did utilise current control groups (Kuusikko *et al.*, 2008; Farrugia & Hudson, 2006; Gillott, 2001). Specifically, Gillott (2001) reports that children with HFA (n=15) scored higher than the controls on both self- and parent-reported measures of social anxiety (n=15). The HFA group also scored higher than normally developing children on separation anxiety and OCD subscales.

In the study by Farrugia and Hudson (2006), higher levels of anxiety were found in the AS group (n=34) in comparison to the control groups (n=30), for both self- and parent-reports. The participants in this study were slightly older (12-16 years) than those in Gillott's (2001) study (8-12 years), and may have been aware of their differences and difficulties, which could explain the correlation found between self- and parent-reports.

### 3.2.3. Anxiety in ASD samples compared to other clinical groups

Of the six studies described in the previous section, three also examine anxiety levels in the ASD samples in comparison to other clinical groups (Farrugia & Hudson, 2006; Gillott, 2001; Russell & Sofronoff, 2005). A further study, conducted by Park *et al.* (2012), examines anxiety levels in children with AS and ADHD.

Gillott (2001) compares the prevalence and nature of anxiety in children with HFA (n=15) and children with Specific Language Impairment (n=15) indicating higher level of anxiety in the HFA group. However, this study is limited in terms of a lack of information regarding sampling techniques and its failure to consider the possible existence of other psychopathologies, which may have confounded the findings.

In Russell and Sofronoff's (2005) examination of anxiety and social worries, no differences are identified in relation to self-reported anxiety between children with AS (n=34) and clinically anxious children. Interestingly, parents and children with AS expressed different views regarding their social concerns, the former reporting more social worries than the children themselves.

In a subsequent study, Farrugia and Hudson (2006) compare anxiety rates between adolescents with AS (n=29) and anxiety disorders (AD; n=34). The results show that the scores for the AS and AD samples regarding self-report and parent-rated scales of anxiety are of comparable magnitude.

The final study using this paradigm, conducted by Park *et al.* (2012), examines differences in anxiety levels and depression between children with AS, ADHD, and depressive disorder (DD). They found that self-reported trait anxiety and parent-reported internalising problems, including anxiety and depression, were higher in the AS sample (n=56) than amongst children with ADHD, (n=56) and just as high as in the group of children with DD (n=56).

#### 3.2.4. Anxiety within ASD sample

Four studies exploring the differences in anxiety levels across ASD subtypes (Kim *et al.*, 2000; Thede & Collidge, 2007; Kuusikko *et al.*, 2008; Tonge *et al.*, 1999) yielded equivocal results regarding the differences in rates of anxiety in AS and HFA groups.

Two of the studies within this category show that children and adolescents affected by Asperger Syndrome suffer from higher levels of anxiety in comparison to those with high functioning autism. Tonge *et al.* (1999) report that 85% of the AS group (n=52) and 65% of the HFA (n=75) group presented with clinically significant levels of behavioural and emotional disturbance.

Similarly, the outcomes of a further study by Thede and Coolidge (2007) show a higher level of Generalised Anxiety Disorder in the AS group (n=16) compared with the HFA group (n=15), measured using the Coolidge Personality and Neuropsychological Inventory for Children (CPNI). Of significance in relation to this study is that the CPNI was not standardised for the ASD population, and the diagnostic differentiations between AS and HFA were made using the survey of autistic symptoms created in reference to general literature on autism and DSM-IV-TR.

Conversely, Kim *et al.* (2000) and Kuusikko *et al.* (2008) found no difference in anxiety rates between those with AS (n=35) and HFA (n=21). In the former study, the parent-reported anxiety rates were similar in children with AS (n=19) and those with autism (n=40). The relatively small AS sample may have affected the outcomes. Nonetheless, Kuusikko *et al.* (2008) found no differences between children with AS (n=35) and HFA (n=21) in regard to any of the self- and parent-report social anxiety measures employed. Of importance is that the parent and child self-reports differed, and the exact size of two groups is not stated.

With respect to differences between children and adolescents with either AS or HFA, Mukaddes and Fateh (2009) found that adolescents (n=14) reported higher rates of anxiety disorders than children (n=23). Kuusikko *et al.* (2008) also found that children with HFA/AS reported an increase in social anxiety as they grew older, while the opposite tendency was observed in children developing normally. Again, these findings should be subject to further academic scrutiny, given they are based on the assumption that younger participants will evolve into adolescents comparable to those included in the study. The trajectory of comorbidities should also be addressed through longitudinal studies.

### 3.3. Anxiety in adults with ASD

#### 3.3.1. Anxiety in ASD samples without comparison groups

Two studies included in this review investigate the prevalence of psychiatric comorbidities in adults with ASD (Lugnegard *et al.*, 2011; Hofvander *et al.*, 2009) without drawing comparisons to other groups.

Of 54 young adults with a diagnosis of AS, Lugnegard *et al.* (2011) identified 30 individuals (56%) with at least one anxiety disorder; of these, 11 individuals met the criteria for two or more anxiety disorder diagnoses. However, this study has significant methodological limitations, notably the selection process and low participation rate, (a high proportion of non-respondents), which compromises the generalisability of the results. The study was clinic-based; although the authors attempted to recruit a representative group, it is noted that ASD might not be representative of the clinic. Comorbidity rate inflation could have also occurred as an artefact of the participants' age at AS diagnosis, with the mental health of those diagnosed late in life potentially compromised due to a lack of adequate support.

Nonetheless, the findings of this study are echoed by Hofvander *et al.* (2009), who identifies anxiety disorders in 50% of the cases. Although the participants in this study were recruited consecutively, making the sample representative, the ASD group included 50 adults with PDD NOS. Both studies used the same method to assess comorbidities, which was not standardised for the ASD population (the Structured Clinical Interview for DSM-IV Axis I Disorders).

#### 3.3.2. Anxiety in ASD samples compared to non-ASD and clinical groups

Only two studies included in this review examine the prevalence of comorbidities in adults with ASD (Joshi *et al.*, 2013; Bejerot *et al.*, 2014).

In the first study, Joshi *et al.* (2013) reports an ASD sample (n=63) had a higher number of lifetime and current comorbidities compared with the age and sex matched non-ASD group. The ASD group showed higher rates of lifetime



comorbidity with multiple anxiety disorders (n=37, 59%). Interestingly, no differences were observed in current psychiatric comorbidities between the ASD and non-ASD samples, although the rate of anxiety was higher amongst adults with ASD compared with the control groups.

The later study by Bejerot *et al.* (2014) offers a more nuanced examination of differences in social anxiety levels between adults with ASD, those with social anxiety disorders and non-ASD adults. The authors found that the ASD group (n=50) scored higher on the anxiety and avoidance subscales of the self-report Liebowitz Social Anxiety Scale in comparison to the non-ASD group (n=53), while the scores for anxiety and avoidance in the SAD group (n=100) were higher than in the ASD and non-ASD groups.

#### **4. Discussion**

The studies summarised in this review undoubtedly contribute to the understanding of the clinical picture of anxiety disorders amongst individuals with ASD without LD. The review findings point towards a high probability of anxiety disorders in the ASD population. However, the methodological diversity of the studies precluded a meta-analysis of the outcomes, and so a comparison of the rates of anxiety across different age groups was not possible. Using the available literature, it was not possible to address the central question of the review, regarding the trajectory of anxiety disorders in ASD populations. Nonetheless, a few firm conclusions can be drawn from the data synthesised, and these appear consistent with those of previous reviews reporting on anxiety amongst individuals with ASD (MacNeil *et al.*, 2008; Mannion & Leader, 2013).

First, the collective outcomes indicate that the prevalence rate of anxiety disorders in this group ranges from 13.6% to 59%. Second, individuals with ASD have heightened levels of anxiety compared to normative or community-based samples. Third, the levels of anxiety experienced by the ASD population are similar to those of clinically anxious individuals. Fourth, individuals with AS are affected by different types of anxiety disorders and their occurrence rates vary with age. There is some indication of anxiety disorders being more severe in adolescents

than in children. Lastly, there are, at present, no unequivocal findings regarding differences in the severity and type of anxiety disorders reported by those with AS and HFA.

Considering the heterogeneity and varying quality of the studies included in this review, their methodological limitations, clinical implications and some recommendations for further research will be discussed below. A particular focus will be also placed on the identification of variables that may impact on the size of the reported prevalence of anxiety in ASD. The weaknesses of the present review will be also addressed.

#### **4.1. Confounding factors and methodological issues of reviewed studies**

The selected studies on the prevalence of anxiety disorders in ASD populations were reviewed and presented in a hierarchical manner guided by their study design, and thus their methodological robustness. Although there are potential benefits to the inclusion of findings from divergent study designs in a relatively circumscribed evidence base, it is difficult to draw meaningful conclusions on prevalence rates from those without control groups. Seven studies included in this review had no comparison groups; in addition, these studies were retrospective, which further limited the control over the data collection. For instance, the inclusion of well-recorded cases only in the study by Park *et al.* (2012) led to the use of a sample unrepresentative of the entire group, and generalisability of the study outcomes is thus questionable.

Furthermore, the reviewed studies employed different selection processes and sample sizes. For instance the participants in studies by Bellini (2004), Mukaddes *et al.* (2009) and Farrugia and Hudson (2006) were informed of research purpose. Mukaddes *et al.* (2009) recruited their participants from referrals to a private psychiatric clinic, suggesting they were individuals seeking treatment and with potentially greater impairment. Consequently, the referral bias might have contributed to the high rate of comorbidity that was observed in this study. The comparison groups in studies by Gillott (2001), Kuusikko *et al.* (2008) and Farrugia and Hudson (2006) were neither screened for autism nor other

psychopathologies. The external validity of these studies is therefore questionable, as the selection processes may have led to either over- or under-inclusion of individuals with AS and anxiety disorders. The low statistical power of further five studies due to either low samples sizes ( $N > 50$  AS/HFA; Bejerot *et al.*, 2014; Farrugia & Hudson, 2006; Gillott, 2001; Mukaddes *et al.*, 2009; Thede & Coolidge, 2006), low participation and response rate (52.6%; Kussikko, 2008; Farrugia & Hudson, 2006) means they may have yielded results that do not reflect actual prevalence rates of anxiety in the ASD population. There was also no indication that *a priori* power calculations were carried out in those studies. Small sample sizes precluded the application of more complex statistical analysis and limited the capacity to control other confounding variables, such as participants' age, use of medication, communication ability, age at diagnosis or peer victimisation. Of particular interest were observations regarding the trajectory of anxiety. Mukaddes and Fateh (2009) concluded that adolescents with ASD suffer from greater anxiety than children, which might be related to an increase in social demands (Kiln *et al.* 2005). Since the study did not include a non-ASD group, it is difficult to judge whether this tendency is in fact unique to the ASD population. Considering adolescents only, the study by Farrugia and Hudson (2006) indicates that adolescents with ASD struggle more with anxiety than their non-ASD counterparts. They also indicated that there was no difference between children with ASD and clinically anxious children. Children with ASD were reported to have higher anxiety in comparison to children with ADHD (Park *et al.* 2012) and speech and language impairments Gillott (2001) reported. This may suggest that the type of comparison group will also need to be considered. In fact, in four studies the normative sample means and historical data were used in control groups (Bellini, 2004; Kim *et al.*, 2000; Thede & Coolidge, 2007; Russell & Sofronoff, 2005). The control groups thus may not reflect current trends and/or the clinical picture of anxiety disorders in the neurotypical population. Given growing evidence indicating an increase in anxieties in the normal population, the comparisons and comparisons of estimates between the ASD group and the non-ASD group may promote misleading conclusions (Twenge, 2000).

Also notable is diagnostic inconsistency given diagnoses of AS and HFA in the reviewed papers were based on two different diagnostic classifications, DSM-IV

and ICD-10. For instance, Tonge *et al.* (1999) applied DSM-IV diagnostic criteria, Kim *et al.* classified participants as AS based on previous work and a literature review, and into the autism category on the basis of the International Statistical Classification of Diseases and Related Health Problems, Tenth Edition (ICD-10). Regardless of the similarities between the two classifications, this inconsistency may cause either over- or under-diagnosis of AS and HFA, and so preclude comparisons of the results (Wilson *et al.*, 2013). In addition to that, in the study of Park *et al.* (2012) there was no standardized procedures employed in diagnostic assessments and diagnoses were made retrospectively, based on data collated from existing records, which rises yet another methodological issue. Similarly, the autism diagnostic assessment of individuals in the study by Mattila *et al.* (2010) was based upon a clinical application of ADI-R and ADOS-2 at a time when neither of the tools had been adapted for a Finnish population.

Of significance is also the risk of inaccurate diagnoses stemming from the difficulty in differentiation between symptoms of anxiety and core features of ASD. First, the diagnosis of OCD in the ASD population is controversial, due to overlapping symptomatology; repetitive, compulsive and obsessive behaviours are integral to the clinical picture of ASD. Mukaddes *et al.* (2009) describe two adolescents, who insisted that their parents sit and walk in a symmetrical manner, or that their mother repeat certain words. Such behaviours are in fact incorporated in the autistic diagnostic algorithm of the ADI-R (Autism Diagnostic Interview – Revised, Le Couteur, Lord & Rutter, 2005). Furthermore, certain examples of specific phobias, such as fear of the sound of wind or loud noises, might be explained in reference to sensory sensitivities that are commonly observed in ASD (Attwood, 2008; Mukaddes *et al.*, 2009).

As indicated by Boyle (1998), measures applied in prevalence studies have implications for their methodological quality. Nonetheless, no study employed anxiety tools with norms for the ASD population or indicated whether the tools have comparative data available for this population. Given the difficulty and controversy surrounding differentiation between anxiety symptoms and core features of ASD, the application of anxiety measures unstandardised for the ASD population raises the risk of underrating and/or overestimating the prevalence of

anxiety disorders. Interestingly, direct observation of participants was used in one study only, and none of the studies used physiological anxiety measures. Clinical interviews, which can offer a more in-depth examination of individuals' cognition and emotional state, were conducted in six instances only.

Second, in three instances, there was no indication whether the employed anxiety measures were reliable and valid (Hofvander *et al.*, 2009; Joshi *et al.*, 2012; Lugnegard *et al.*, 2011) and in further two studies, the authors failed to specify whether they had used valid anxiety tools (Kim *et al.*, 2000; Russell & Sofronoff *et al.*, 2013). In the study by Russell and Sofronoff's (2005) none of the children in the AS sample had a clinical diagnosis of anxiety. This clearly indicates a serious limitation in terms of the reliability of the outcomes.

Third, the conclusions regarding the presence of anxiety symptoms were derived from self- and/or parent-reports, which were often inconsistent. This points towards the type of informant as another important variable. The quality of parent-reports may be confounded by parents' own anxiety or other mental health problems (Mattila, 2010; Mukaddes, 2009). The cross-sectional design of studies precluded the identification of casual relationships between parental anxiety and symptoms of their children's emotional and behavioural difficulties. In the studies by Kuusikko *et al.* (2008), Farrugia & Hudson (2006) and Gillott (2001) parents of children with HFA and AS rated their children's social concerns higher than the children themselves did, which can potentially be explained by the poor introspective capabilities of children with ASD (Bennett, 1989). It is postulated that the development of cognitive-emotional skills and self-consciousness takes longer in children with AS/HFA compared to normally developing children. Individuals with ASD may also be less capable of accurate symptom reporting, and/or may have little insight into their feelings and emotions. Given their communicative deficits, along with other difficulties labelling and differentiating between different emotions, judging the emotional gradient, and tendency toward extreme and polarised thinking ('all or nothing' thinking), self-reports may not truly reflect either the actual emotional states of participants or the actual grade of the experienced emotions.

The methodological flaws described above should guide and inform future research.

#### **4.2. Clinical implications and future research**

Notwithstanding the limitations and variance in the outcomes, there is evidence of some consensus that anxiety disorders tend to coexist with AS/HFA, implying a need for further scrutiny of this interplay and its implications.

First, it seems reasonable to incorporate a routine mental health check into the autism diagnostic assessment process. Although differentiation between anxiety disorders and ASD has proven to be complex due to significant symptomatological overlaps between the two, therapeutic interventions should be condition-specific to ensure their effectiveness. Second, there is a risk of perceiving anxiety disorders as being a direct consequence of ASD, which could potentially limit the provision of adequate anxiety treatments for those with ASD. Research on the typically developing population indicates that negative peer interactions could contribute to the emergence of anxiety (LA Graca & Lopez, 1998). It is therefore reasonable to suggest that those with ASD are at a higher risk of suffering from anxiety, which can justify the need for specialist services to offer support focused on the management of ASD symptoms as well as psychiatric comorbidities. Given how scarce the specialist services are in the UK, the emphasis needs to be placed upon the provision of specialist training for mental health practitioners to enable them to provide adequate interventions as well as improvement of accessibility to traditional services for those with ASD. Third, co-existent anxiety in ASD may exacerbate the autistic presentation and subsequently lead to the erroneous classification of the severity of ASD. This is particularly vital given the new diagnostic guidelines and criteria introduced by the DSM-V, according to which clinicians must specify the severity levels for social communication and restricted interests, and repetitive behaviour. Lastly, given the high prevalence of anxiety disorders in ASD, it seems equally important to screen individuals suffering from anxiety for autism.

As noted by Boyle (1998), the methodological value of prevalence studies is largely dependent on the quality of sampling, measures and suitability of statistical analyses. Taking into consideration the weaknesses of the reviewed studies, future research should be driven by both practitioners and researchers, and take note of the following recommendations:

1. Studies should include current non-ASD comparison groups matched on significant factors, such as age and intellectual capabilities. The non-ASD groups should be screened for autism and psychiatric conditions.
2. The ASD groups should include individuals whose diagnoses were based upon the application of the same diagnostic criteria. This is particularly vital following the introduction of the DSM-V that favours different diagnostic criteria to DSM-IV and ICD-10. The age at diagnosis should be considered, as well as the use of medication or previous anxiety treatments when forming a research group.
3. Anxiety should be measured using multimodal and multisource assessments. The involvement of practitioners with an expertise in ASD appears to be invaluable when conducting observations and semi-structured interviews to evaluate anxiety disorders and differentiate between anxiety and the core symptoms of ASD. These observations should be carried out with several informants (e.g. parents, teachers, care coordinators), and the instruments measuring anxiety should be valid, reliable, and offer comparative data for the ASD population.
4. Future studies should provide adequate descriptions of research groups, selection processes, procedures, instruments, and statistical analyses to facilitate replication.
5. A longitudinal study design should be applied in order to measure changes in the prevalence of anxiety in the ASD population across the lifespan, and thus to establish the trajectory of anxiety disorders in ASD population. This could potentially promote the development of anxiety prevention programmes.

### **4.3. Literature review limitations**

Several limitations to this review should be noted. First, all non-English language publications were excluded. Furthermore, there is no standard method for conducting an evaluation of studies reporting on prevalence (Munn *et al.*, 2014) and so different appraisal tools are used in systematic reviews. The heterogeneity of the reviewed studies and consequently the narrative approach to synthesis employed in this review precluded the identification of a trajectory of anxiety disorders in ASD. Nevertheless, this review is a first attempt to examine the prevalence of anxiety in the ASD population without LD.

### **5. Conclusion**

Individuals with ASD without LD are commonly considered to be at higher risk of developing anxiety disorders than those with LD. The reviewed studies indeed point toward a high prevalence of anxiety disorders in the ASD population. The levels of anxiety amongst individuals with ASD are comparable to those of clinically anxious individuals. It is therefore important to screen for anxiety following an autism diagnostic assessment, and to promote the development and provision of adequate anxiety treatments in ASD.



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## Appendices

### Appendix A. Guidelines for Authors: Target Journal for Literature Review

The *Journal of Autism and Developmental Disorders* is the leading peer-reviewed, scholarly periodical focusing on all aspects of autism spectrum disorders and related developmental disabilities. Published monthly, *JADD* is committed to advancing the understanding of autism, including potential causes and prevalence (e.g., genetic, immunological, environmental); diagnosis advancements; and effective clinical care, education, and treatment for all individuals. Studies of diagnostic reliability and validity, psychotherapeutic and psychopharmacological treatment efficacy, and mental health services effectiveness are encouraged. *JADD* also seeks to promote the well-being of children and families by publishing scholarly papers on such subjects as health policy, legislation, advocacy, culture and society, and service provision as they pertain to the mental health of children and families. Review articles are solicited in targeted areas of special interest; book and media reviews provide targeted updates on important new materials; and the Ask the Editor column serves as a forum for addressing timely questions of relevance to *JADD*'s broad readership.

- MANUSCRIPT FORMAT

All *JADD* manuscripts should be submitted to Editorial Manager in 12-point Times New Roman with standard 1-inch borders around the margins.

#### APA Style

Text must be double-spaced; APA Publication Manual standards must be followed.

As of January 20, 2011, the Journal has moved to a double-blind review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to *JADD*, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.

The blinded manuscript containing no author information (no name, no affiliation, and so forth).

#### The Author Note

The preferred article length is 20-23 double-spaced manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 double-spaced pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.

- TEXT AND PRESENTATION

Submit your material in PDF format; .doc or .ppt files are not suitable for long-term viability.

A collection of figures may also be combined in a PDF file.

- ABSTRACT

Please provide an abstract of 120 words or less. The abstract should not contain any undefined abbreviations or unspecified references.

- KEYWORDS

Please provide 4 to 6 keywords which can be used for indexing purposes.

- TEXT FORMATTING

Manuscripts should be submitted in Word.

Use a normal, plain font (e.g., 10-point Times Roman) for text.

Use italics for emphasis.

Use the automatic page numbering function to number the pages.

Do not use field functions.

Use tab stops or other commands for indents, not the space bar.

Use the table function, not spreadsheets, to make tables.

Use the equation editor or MathType for equations.

Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).



Please use no more than three levels of displayed headings.

Abbreviations should be defined at first mention and used consistently thereafter.

All tables are to be numbered using Arabic numerals.

Tables should always be cited in text in consecutive numerical order.

- **ETHICAL RESPONSIBILITIES OF AUTHORS**

This journal is committed to upholding the integrity of the scientific record. As a member of the Committee on Publication Ethics (COPE) the journal will follow the COPE guidelines on how to deal with potential acts of misconduct.

To ensure objectivity and transparency in research and to ensure that accepted principles of ethical and professional conduct have been followed, authors should include information regarding sources of funding, potential conflicts of interest (financial or non-financial), informed consent if the research involved human participants, and a statement on welfare of animals if the research involved animals.

Authors should include the following statements (if applicable) in a separate section entitled “Compliance with Ethical Standards” when submitting a paper:

- Disclosure of potential conflicts of interest
- Research involving Human Participants and/or Animals
- Informed consent

## **PART TWO: SERVICE EVALUATION**

### **Evaluation of referral patterns and referral processes in the \*\*\* Service**

## **Executive Summary**

The Department of Health continues to improve the provision of health care services across England. The Single Point of Access (SPA) was one of the initiatives introduced to enhance the accessibility to care and treatment. There is strong evidence of the increased efficiency in managing the workflow in health services following the streamlining of referral processes.

Currently there is no single referral route to Learning Disability Services in A and B. There was also no data on referral patterns in both services, which may undermine optimal allocation of resources across two localities. This service evaluation followed two sets of enquiries about referral patterns and referral processes, including currently used referral forms. First, it aimed at producing clear overview of the referral flow including a number of appropriate and inappropriate referrals and re-referrals, waitlists, lengths of involvement and number of practitioners involved in one case between the period of November 2014 and April 2015. The data extracted from RiO was used to address the referral patterns. Second, it explored the efficiency of the existing referral processes and usefulness of the current referral forms through the exploration of experiences of referral processes and referral forms amongst practitioners and administrators. Thus, a set of questions was developed to guide focus groups and collate information on their experience of current referral process and referral forms within the Learning Disability Services. Ten staff members took part in the study, that is, five clinicians and four administrators, who formed two separate focus groups. Their narratives were then analysed and interpreted using the template analysis.

The findings of the evaluation revealed no significant differences in referral patterns in Learning Disability Services under examination. The number of referrals received within the sampling frame of 6 months was similar for each service, as were wait times. The limitations imposed by the RiO did not allow to answer questions regarding the number of re-referrals and a possible correlation between the type of problem (reason for referral) and waiting time.

The second line of enquiries focused on the experience of managing, coordinating and processing referrals and the use of the current referral forms. Both clinicians and administrators pointed out towards the differences in referral processes between two localities. Although there was no strong inclination to favour one locality over another, the need to unify and improve the existing systems was evident. First, the referral processes were not clear for the majority of the respondents and were lacking systematicity. Second, there were no guidelines that define the stages of the referral processing and staff members' responsibilities. Fourth, there was a number of different referral forms used internally and externally.

Based upon the identified weaknesses in referral processes and referral forms, the participants provided their views on how these could be improved. The need to streamline the referral processes was voiced by majority as well as the need for clear guidelines for all involved in the coordination and processing of referrals. Both practitioners and administrators discussed the possibility of having up to two referral forms for internal and external referrals that would provide all the essential information required for their smooth processing.

The findings were fed back to the clinical team including the joint managers of \*\*\* Services. Subsequently, it was requested to develop a new referral form and create one Single Point of Access for all the referrals to \*\*\* Services. One referral form was developed in line with the feedback collated in focus groups. The form was then discussed in more detail in the Psychology Meeting and emailed to practitioners and administrators for comments. The final version of the form along with the information on the Single Access Point, one posting and email address, were approved in the Governance Meeting (insert date).

## **1. Introduction**

### **1.1. National context**

Health services can be argued to comprise semi-autonomous health professionals in loose networks. Healthcare teams are made up of a range of professionals with varying expertise. Referrals to individual specialists within a single service indicate that the service has multiple access points, accompanied by different referral forms, addresses and procedures. To reduce the inefficiencies associated with this traditional arrangement, and improve the way referrals are received and managed, a Single Point of Access (SPA) was introduced (Department of Health Equality and Excellence: Liberating the NHS (2010)). Since then the SPA has been rolled out in diverse settings: primary care, emergency care, health and social rehabilitation, and outpatient mental health services. The Department of Health has considered the SPA to be a unified gateway to multiple departments working together within a single service.

Many services across England have introduced the SPA in recent years. For instance, in 2012 the Hertfordshire Partnership University NHS Foundation created an SPA team consisting of administrators and clinical advisors, whose responsibility was to receive all referrals, screen these for urgency and divide into 'urgent' and 'routine' pathways. Thus, instead of referrals being sent to 34 access points, which corresponded with 34 different teams within the Trust, all referrals were sent to the SPA. This centralisation appeared to deliver improvements; the Trust reported itself was in a better position to maintain consistent service delivery, informed by a clear overview of demand and activity. The referrers clearly understood the process of making referrals, and the system proved more cost effective (HPFT.NHS.UK Summer 2012 Newsletter; HPFT Briefing for HSC, 2013).

### **1.2. Local context**

The \*\*\* Service provide specialist diagnostic assessments and specialist psychological interventions for adults with neurodevelopmental conditions. The \*\*\* Service comprise three separate services for those diagnosed with Learning

Disability (LD), Attention Deficit and Hyperactivity Disorder (ADHD) and Autism Spectrum Conditions (ASC) across two geographically co-terminous localities: A and B. The \*\*\* Service is delivered by Clinical Psychologists, Counselling Psychologists, Specialist Counsellors, Psychiatrists, Behavioural Analysts, Challenging Needs Practitioners and Senior Support Workers.

This service evaluation focuses on the referral patterns and processes within the largest part of the \*\*\* Service, which is the Learning Disability Service (LDS). The recent staff changes within the LDS highlighted the need to evaluate the workload and workflow within this service in order to allocate new resources accordingly. There was no similar audit conducted in this part of the service in the past (see Appendix B).

Currently there is no single referral route to the Learning Disability Services. Referrals are sent either to administrators or directly to clinicians based in three different locations. In B, the referrals are screened against eligibility criteria at point of intake, so that only appropriate referrals are passed onto the LD Team Meeting. In A, all referrals are forwarded onto the LD Team Meeting. All the appropriate referrals from both localities are then discussed in more detail at a Psychology Allocation Meeting. If referrals provide sufficient information on a client and their needs, these are allocated directly to a Clinician. Otherwise, an Assistant Psychologist is asked to collate further relevant information (fact-finding).

There were 9 different referral forms identified that are used internally and externally. At the time of this service evaluation, the \*\*\* Service used the RiO electronic data recording system to log all referrals and record clinical data.

### **1.3. Aims**

This service evaluation will focus exclusively on the Learning Disability Service in A and B, which is a part of the \*\*\* Service. The aim of this study is twofold:

- To explore the referral patterns within the Learning Disability Service in A and B between November 2014 and April 2015.

- To explore the perspectives of practitioners and administrators regarding the current referral processes and referral forms.

It was expected that information relating to referral patterns within Learning Disability Service in A and B could help to inform the appropriate allocation of resources across two localities. Specifically, the following questions were addressed:

- How long do clients wait for an appointment following their referral?
- Does the wait time vary according to the type of problem?
- How many inappropriate referrals were received?
- How long do clients remain open/active?
- How many professionals are involved in one case simultaneously?
- How many re-referrals were received?
- What were the reasons for the re-referrals?

It was assumed that the opinions of key staff members involved in referral coordination and management would provide the grounds for service improvement.

## **2. Method**

### **2.1. Design**

The evaluation of referral patterns within the Learning Disability Services was possible through the analysis of the data extracted from the RiO, an electronic service user record system. A 6- month period, that is, the period between November 2014 and April 2015 was considered sufficient to obtain a clear overview of demands and activity. The Information Analyst, the RiO champion was provided with the selected parameters that were used to extricate information from the RiO in the form of Excel sheets. Thus, the names of clients referred to the Learning Disability Services within the 6- month period along with their demographic characteristics, number of days each of them waited for their first contact (wait time), reasons for their referrals (type of problem), names of practitioners involved in each case (number of practitioners involved in each

case), open and close date (duration) were extracted. In instances where the records were incomplete, the missing information was extracted from the Allocation Meeting Minutes. All the calculations were carried out manually.

The relevant information regarding practitioners' experience of current referral processes and referral forms was collected through two focus group interviews. Prior to conducting the interviews, a set of questions was developed in consultation with \*\*\*, Consultant Clinical Psychologist, Joint Service Manager (see Appendix C). The questions were used to prompt a dialogue, while allowing participants to explore the salient issues in a flexible manner. Due to time constraints and practitioners' workloads, the participants' views were explored via two separate focus groups, each lasting approximately 1.5 hours. The two focus groups were made up of six clinicians and 4 administrators, respectively; they were selected to take part in this study due to their direct involvement in managing, coordination and processing of the referrals. Their responses and narratives were recorded in writing.

## **2.2. Participants**

The quantitative data used to evaluate the referral patterns in the Learning Disability Services were derived from the RiO and calculated accordingly.

The evaluation of referral processes and currently used referral forms was based upon the exploration of experiences of ten staff members: six clinicians and four administrators. It was assumed that the examination of their perspectives would shed light on the effectiveness of the existing referral processes and the quality of the currently used referral forms.

All ten participants were contacted via email following a verbal explanation of the purpose of the study at the monthly Departmental Meeting. They were informed of their voluntary participation and that they had the right to withdraw at any point.



## **2.3. Analysis**

The data extracted from the RiO electronic database was analysed using Excel.

The focus group transcripts were analysed and interpreted using template analysis. This approach was considered the most conducive to the study aims for three reasons; first, it allows for *a priori* codes to be identified in advance, which help guide the analysis. Second, it is sufficiently flexible and so can be adapted to the needs and the requirements of a particular study (King, 1998). Third, it focuses more on across case rather than within case analysis (Brooks *et al.*, 2015). In this instance, the theoretical position was predetermined by its narrow and clearly defined purpose that was reflected in the set of questions used in focus groups. Thus, the questions laid the foundation for the emergence of several *a priori* themes. These included: the strengths and weaknesses of the current referral processes; improvement of the referral processes; the quality of current referral forms; and improvement of referral forms. As such, they formed the initial template that was used to guide analysis and interpretation.

Thus, the interview transcripts were organised according to the predefined themes, which produced the initial template. This was then modified accordingly, allowing for the *a priori* themes to be further refined and new themes to be included. Sub-codes were derived through a process of immersion/crystallisation by re-reading the text. Subsequently, the final template was formed (see Appendix D).

## **3. Results**

### **3.1. Referral audit**

The audit of referrals revealed that 55 referrals were received by the Learning Disability Services between November 2014 and April 2015. All referrals were deemed appropriate, that is, they met the referral criteria, and were processed accordingly. Of these, 31 were received by the A Learning Disability Service, whilst the B Learning Disability Service received 24 referrals. A total of 55

referrals were processed and completed during the 6-month evaluation period. The difference between the number of referrals accepted between A and B Teams were insignificant ( $p=.18$ ). Table 1 shows the selected sociodemographics of clients referred to the Learning Disability Services in A and B. These were the only sociodemographic characteristics available on RiO.

| Characteristics            | A referrals | B referrals |
|----------------------------|-------------|-------------|
| Referrals accepted         | 31          | 24          |
| Gender                     |             |             |
| <i>Female</i>              | 8           | 10          |
| <i>Male</i>                | 23          | 14          |
| Age                        |             |             |
| <i>Average</i>             | 40.4        | 34.5        |
| <i>Median</i>              | 43          | 30.5        |
| Age range                  |             |             |
| 17 – 27                    | 8           | 7           |
| 28 – 37                    | 5           | 11          |
| 38 – 47                    | 8           | 1           |
| 48 – 57                    | 5           | 4           |
| 58 – 67                    | 4           | 0           |
| 68 - 77                    | 1           | 1           |
| Ethnicity                  |             |             |
| <i>Unknown</i>             | 10          | 14          |
| <i>White – English</i>     | 19          | 6           |
| <i>White – Other</i>       | 1           | 0           |
| <i>Asian/Asian British</i> | 0           | 1           |
| <i>Black/Black British</i> | 1           | 0           |

**Table 4. The sociodemographic characteristics of clients referred to A and B**

The ethnicity of clients referred to the B and A Learning Disability Teams reflect the ethnicity of the general population in the two boroughs. The differences in gender and age of clients referred to two teams were statistically insignificant ( $p=0.2$  and  $p=0.54$ , respectively).

The waiting times and number of practitioners involved in any case were similar across the two localities. Table 2 shows the waiting times and number of professionals involved in a single case.

|  | A referrals | B referrals |
|--|-------------|-------------|
| Waiting time in days for first contact | 43.1        | 42.9        |
| <i>Average</i>                         | 159         | 130         |
| <i>Max</i>                             | 0           | 4           |
| <i>Min</i>                             |             |             |
| Number of practitioners involved       | 2           | 1.5         |
| <i>Average</i>                         | 5           | 5           |
| <i>Max</i>                             | 1           | 1           |
| <i>Min</i>                             |             |             |

**Table 5. Waiting times and professionals' involvement in A and B.**

Due to limitations and inconsistencies in RIO entries it was not possible to answer all of the questions specified in the audit proposal. Thus, the questions regarding the correlation between wait time, type of problem and number of re-referrals remained unanswered. Furthermore, on 18<sup>th</sup> September 2015 the RiO was replaced with a new electronic record system, Care Notes, and so it was not possible to retrieve data using new parameters.

### **3.2. Practitioners' perspectives**

#### **3.2.1. Referral processes**

##### ***Differences in referral processes between two teams***

Participants in both focus groups reported differences in referral processes between the B and A LD Services. It was highlighted that historically the A LD Team Meetings have been arranged jointly with Social Services, which has not changed since. This was perceived as an opportunity to discuss referrals instantaneously and in detail. Nevertheless, the participants' opinions did not favour one service over the other, but merely clarified the differences between the two:

*'There is a difference between the two teams in terms of efficiency. In A the referrals are discussed in more detail because the referrers are usually present, so referrals can be clarified straightaway. In B there is no chance to talk to a*

*referrer, so there might be a delay in processing referrals if fact finding is required’.*

*‘In B the processes [concerning Health and Social Care Services] are separate, but in A they are not. It is therefore less clear [in B] who the referral is for’.*

*‘The Social Services have more background information on clients, so questions can be answered promptly’.*

*‘At the A LD meetings there is a possibility to talk to Social Services directly and get additional information about the client. This might help in keeping the [referrer’s] expectations realistic.’*

*‘The processes at the B site seem to be more efficient; meetings are well structured and decisions are made more quickly, probably because there are fewer people in attendance’.*

### ***Lack of clarity regarding referral processes***

There was a general consensus between participants regarding the lack of clarity in the referral system and referral routes.

*‘It varies between teams, even though the system is supposed to be the same. (...) The referral coordination relies on individuals because there is no system in place. If the key people are not present at the meeting, the process can be slowed down’.*

It was highlighted that the external referrers might not know where to send the referrals, and practitioners themselves make internal referrals in different ways. It appeared that, overall, understanding of the referral routes is not sufficient.

*‘The referrer might not know who and where referrals should be sent to, and this might make the referral processes not clear’.*

*‘It is not clear how and where to send referrals’.*

*'The route is not clear for people to understand (...) there is some confusion about where to send referrals'.*

*'There is no clear picture of this process'.*

*'Referrals are not sent to the same place, and members of the team might not know where the new referrals are actually kept'.*

*'Not all team members make referrals the same way'.*

*'I am not sure if all team members know where referrals should go first'.*

Some of the participants voiced their doubts about the positioning of the service in the community, which may also cause confusion around external referrals.

*'Referrers might not be aware of what we actually offer. To make a referral they need to know what we do'.*

*'Other services might not even know we exist'.*

In 2015 the \*\*\* changed its name from \*\*\* to \*\*\*. Also, the LD A Service moved from \*\*\* to \*\*\*. Participants queried whether these changes might have caused some confusion amongst external referrers.

*'Information regarding the move has not yet been communicated externally, and therefore there is some confusion regarding where to send the referrals'.*

*'Routes are clear; people are just not aware of the move'.*

*'The recent change of name might be confusing'.*

A few participants stated that the referral system relies on individuals rather than processes. In addition, the absence of a Clinician in one of the meetings may inhibit the processing of making a referral.

*'Key people [clinicians and administrators] have to be at the meeting. Otherwise some important information might be lost and the process will be slowed down. The process relies on individuals, and not a system'.*

*'Often professionals have some knowledge of the client or the context, which facilitates decision-making. If they are not present, the process takes longer'.*

*'The referral processes depend on individuals and not on a functioning system'.*

### ***Improvement of referral processes***

All participants believed that there is a scope for the improvement of referral processes. Almost all participants highlighted the importance of having clear instructions with regard to how referrals should be processed.

*'There should be written guidelines for admin. This would make the processes cleared'.*

*'No, the route is not clear. This is because of a lack of communication and information. Maybe clearer guidelines should be communicated so that everyone knows what to do'.*

Furthermore, the loss or delays in the referral processes were attributed largely to the lack of a robust system or guidelines. Although, only one respondent reported on a referral being lost.

*'The referral was lost in May, but it was not eligible. The referral has been sent a few times and it has not been clear who was supposed to answer the referrer'.*

*'It would be good to make it clear what is admin and what is clinical work. Some of the work being done by clinicians today could be done by admin to facilitate the process'.*

Many of the participants referred to a single point of access as being a potential way of improving the referral flow.

*'There is no clear overview of referral patterns and pressure points in the organisation, which could improve understanding of the flow of referrals. Maybe the referrals could be distributed from one point'.*

*'The referrals are sent to different people. It is confusing. Having one access point would make it clearer for the external referrals'.*

### **3.2.2. Referral form**

#### ***Number of referral forms***

The majority of participants pointed out that misunderstanding exists around which referral form should be used for internal referrals. This led to the belief that external referrers might be equally confused about the selection of the appropriate referral form. In fact, nine different referral forms are currently used internally and externally.

*'Too many referral forms are being used, which is confusing'.*

*'First of all, it is not clear which referral form to use'.*

*'Often I do not know if I am using the right form. It must be even more confusing for external referrers'.*

#### ***The quality of information in referral forms***

All participants reflected on the quality of information provided by a referral using any of the referral forms. It appears that the referral forms are often incomplete, which may delay their processing.

*'There might be a need to be tougher when a referral is received. If there is not sufficient information, we should send the form back and request further information'.*

*'There is usually not enough information to process the referral'.*

It was reported by many participants that it is difficult to establish the reason for a referral based only upon information provided in the form; the clinical need is not clearly formulated, nor the type of intervention required.

*'It is vague, and many of the referrals come with general queries, which makes it difficult to know what kind of help is requested. The need that is described in the form is not always what is actually needed. This becomes clear after a direct contact with the client'.*

*'It is not clear on the form what they are requesting'.*

*'We need certain information to process referrals appropriately'.*

Concerns were also raised about client consent and risk, which similarly may delay the processing of referrals.

*'We need to check with referrers if clients are actually aware of being referred to us'.*

*'Risk information is not included'.*

*'There is no information about risk on the form'.*

### ***Improvement of referral forms***

All participants voiced the need to reduce use just one or two referrals forms. It was suggested that the referral form could be downloaded and printed off, or emailed direct to the service.



*'We should have one or two referral forms that are short enough to enable the referrer to fill them out correctly'.*

*'Yes, current forms are not formatted correctly and it is not an online form. It should be easily accessible, for instance, from our website'.*

The focus group discussions also centred on the content of the referral form. The majority of participants agreed that the form should include general information about a client, a clearly defined request and details about the clients' existing support network. Others emphasised the importance of obtaining information surrounding risk and consent, and ensuring that the referrer is aware of their responsibility over a client.

*'The form should provide all the relevant information. Besides the general information, we should know who is involved and whether consent was obtained. The need for our involvement should be clear'.*

*'It needs to be clear what exactly we are being asked to do, and why'.*

*'I think one of the issues is risk. We should be aware of these from the beginning'.*

*'Maybe having tick boxes for the type of input, so what kind of work is required, direct or indirect work with a client'.*

*'Definitely, information about the referrer's responsibility over a client [is needed]'.*

All participants agreed that close attention should be paid to the implementation of a new form, if it were to be introduced.

*'Once the form has been created it needs to be properly introduced to the entire team and to external professionals to make sure it is used appropriately'.*

*'It will take some time to replace all of the existing forms with one form. This form should be circulated amongst all relevant professionals'.*

## **4. Discussion**

### **4.1. Interpretation of results**

Between November 2014 and April 2015 Learning Disability Services received a total of 55 referrals. All of these referrals were appropriate and processed accordingly. Irrespective of the higher number of referrals received by the A Learning Disability Service (n=31) compared to the B Learning Disability Service (n=24), the waiting times and the number of professionals involved in processing referrals were similar.

Due to inconsistencies in data entries and the limitations of the RiO system it was not possible to clarify whether the wait time was correlated with the type of problem being referred. The electronic data record system used at the time (RiO) was not able to identify the number of re-referrals across both teams. It is therefore important to highlight it as the main methodological weakness of referral audit. Thus, the set of questions regarding referral patterns was developed in a vacuum, without the full understanding of the configuration of the RiO.

The evaluation of staff members' perspectives on referral processes provided valuable insight into the weaknesses and inconsistencies of the current referral system within the \*\*\*. First, it appears that the referral processes in the two localities are different, which may stem from the historical arrangements between the Health and Social Services. Notwithstanding these differences, practitioners highlighted the respective advantages and disadvantages of the two services. It was noted that in the B Learning Disability Service the referrals are discussed within a smaller circle of professionals, which gives an impression of meetings being well structured. However, the joined-up working of the Health and Social Services in A was thought to facilitate instantaneous clarification of referrals, which translates into less time being required for fact-finding.

Second, the most evident theme emerging from the practitioners' narratives suggested a need to develop a clear referral pathway and explicit guidelines for all practitioners. The processes are not clear for both clinicians and administrative staff. It was pointed out that certain tasks might be better allocated to administrators, as this would enable clinicians to attend to clinical matters more effectively. It appears that a clearer referral process might also help to define the responsibilities of those involved in the coordination, processing and managing of referrals. The participants felt that having a well-established referral system would reduce delays in the processing of referrals.

Third, practitioners agreed that having one access point would allow for better coordination and processing of referrals. Currently, referrals are sent to either administrators or clinicians in paper format, or electronically to a generic or clinician email address. This means that the referral processes rely on individuals rather than a robust system, which was perceived by the participants as being a major weakness.

Fourth, different referral forms are being used by internal and external referrers. Consequently, the quality of information derived from the referrals form varies.

#### **4.2. Implications for service development**

The referral audit and exploration of the views and opinions of practitioners and service administrators have informed the following recommendation for service development:

1. The differences in the referral intake between the A Learning Disability Service and the B Learning Disability Service are not significant.
  - a. Therefore, it can be assumed that the resources allocated are appropriate to meet the demands of the referrals to both services.
2. Practitioners should be provided with clear instructions regarding how to record their interventions, in order to maintain consistency and aid future audits.

3. The referral processes in the Learning Disability Services in A and B are different; they are not clear to practitioners, nor most likely to external referrers.
  - a. The referral processes should be clearly defined and communicated to practitioners and administrators.
  - b. The referrals should be screened at point of intake against the eligibility criteria and forwarded to the appropriate Learning Disability Team Meetings for discussion.
4. The service should establish one single point of access.
5. One referral form should be developed and used for all internal and external referrals.
  - a. The referral form should be downloadable and returned either by post or electronically.
  - b. In addition to background information about a client, the referral form should include information on consent, risk and the presenting problem, to enable processing in a timely manner.
  - c. The referral form along with the \*\*\* Service leaflet should be sent to the external referrers (i.e. GP surgeries, Social Services, CMHT, etc.)
6. The changes in the referral processes/forms should be monitored and their impact should be evaluated in 12 months.

#### **4.3. Dissemination and implementation**

The findings with recommendations were fed back and discussed with the Clinical Team and Service Managers in the monthly Psychology Meeting. These were well received by the team.

Considering the factors outlined in the Diffusion of Innovation Theory, it was assumed that the recommendations would be welcome with openness as long as they can be perceived as being better than previous options, consistent with the existing values, easily understandable, compatible with the needs of staff members, testable and leading to visible results. The suggestions for improvements were derived from the opinions and views of the clinicians and

administrators rather than imposed by the managers, which may indicate their motivation to implement changes. There was also an overall consensus amongst the staff members as to how to make the referral flow more efficient. While presenting the recommendations to the team, the emphasis was placed on the need to develop guidelines to ensure that both clinicians and administrator know their roles in the referral processes.

The draft of a new referral form was also presented in the Psychology Meeting. Further comments were made in relation to editorial aspects of the form. Subsequently, the proposed form was emailed to practitioners and administrators within the \*\*\* Service with a request for suggestions. In this manner both clinicians and administrators maintained their active involvement in the service redevelopment. The final version of the referral form featuring one postal/email address, a single point of access, was approved by the Clinical Governance (please see Appendix E).

The effect of the suggested changes should be evaluated in 6 months time. Thus, the clinicians and administrators should be provided with an opportunity to comment on the efficiency of the new referral system.

The summary of the audit will be submitted to the Governance Committee and saved in the Psychology Confidential Folder on the shared drive for the practitioners and administrators to access it.

## **5. Critical appraisal**

This service evaluation is not without limitations. First, not all the questions regarding the referral patterns in Learning Disability Services were answered. It was assumed that the RiO electronic record system would permit use of a larger number of data manipulation algorithms. In the process of data collection, it became apparent that the choice of parameters is in fact very limited. For instance, it was not possible to extract data concerning the number of re-referrals and a

possible correlation between wait time and the type of problem being referred. This was further complicated by a number of inconsistent entries.

Second, due to time constraints and clinicians' workloads, participants were divided into two focus groups. The result was that administrators and clinicians were interviewed separately, which may have reduced the richness of their narratives somewhat. It was explained to the participants that this division was not intentional.

Third, only ten staff members took part in the service evaluation. Although this number may seem low, the participants were selected based upon on their direct involvement in coordination, management and processing of referrals in the Learning Disability Services in A and B. Their views might not be representative of the entire Learning Disability Services, but they were able to provide in-depth accounts of their direct experiences.

Fourth, the primary purpose of the service evaluation and the set of questions used to guide the focus groups brought a number of pre-defined codes to the surface, which may have hindered the emergence of new codes.

Notwithstanding its limitations, the scope and nature of this project were service driven and the responses to the findings and recommendations were positive and constructive. One of the most significant and immediate effects of this service evaluation was the development of the unified referral form and the single point of access. The actual impact of these changes and the implementation of the remaining recommendations should be checked in 6 months time.

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## Appendices

### Appendix B. Approval of the Audit Proposal.

Audit Proposal Form (APF)

Please complete **ALL SECTIONS** of the form and forward to:

[Redacted contact information]

|                   |                   |
|-------------------|-------------------|
| (Office use only) |                   |
| Date Received:    | Audit Ref. Number |

|  |                                     |
|--|-------------------------------------|
| 1(a) Audit lead details  |                                     |
| Name: Joanna Beckett   | Job title: Clinical Psychologist    |
| Work Address: [Redacted] 4DY   |                                     |
| [Redacted]   | [Redacted]                          |
| 1(b) Audit Title:<br>Evaluation of the referral patterns in the Neurodevelopmental Service: [Redacted] Learning Disability Team and [Redacted] Learning Disability Team. |                                     |
| Audit start date:<br>26 May 2015   | Audit end date:<br>20 December 2015 |

|  |  |   |
|--|--|---|
| 1(c) Please tick ✓ one box: Is this Audit a:   |  |   |
| Clinical Audit (eg, Measures a standard) <input type="checkbox"/>  | A Service Evaluation (eg, Patient Survey) X <input type="checkbox"/> |   |
| 1(d) Which Care Quality Commission Outcome, NHSLA Standard or National Best Practice Standard / NICE guidance does this audit relate to: Please tick ✓ relevant boxes or describe: |  |   |
| Involvement & Information<br><input type="checkbox"/>  | Personalised care, treatment & support<br><input type="checkbox"/>   | Safeguarding & Safety<br><input type="checkbox"/>     |
| Suitability of Staffing<br><input checked="" type="checkbox"/> X   | Quality & Management<br><input checked="" type="checkbox"/> X        | Suitability of Management<br><input type="checkbox"/> |



2 (a) Overall Audit aims, e.g, purpose of the audit?

The main aim of audit is to examine the external and internal referral patterns and processes across [redacted] Learning Disability Team and [redacted] Learning Disability Team to ensure the efficiency of the service provision. This audit focuses on learning disability referrals only. Separate audits will address dementia, ADHD and ASC referrals.

2(b) Specific objectives. What are the audit guidelines or standards being measured?

This service evaluation aims to answer the following questions:  
 How long do clients wait for an appointment following their referral in [redacted] Psychology LD Team and [redacted] Psychology LD Team?  
 Does the wait time vary with the type of problem?  
 What is the number of inappropriate external referrals to [redacted] Psychology LD Team and [redacted] Psychology LD Team?  
 What is the number of inappropriate internal referrals within [redacted] Psychology LD Team and [redacted] Psychology LD Team?  
 How long do the clients remain open/active to professionals in [redacted] Psychology LD Team and [redacted] Psychology LD Team? (length of the activity)?  
 How many professionals are involved in one case simultaneously in [redacted] Psychology LD Team and [redacted] Psychology LD Team? (intensity of work)  
 What is the number of re-referrals to [redacted] Psychology LD Team and [redacted] Psychology LD Team?  
 What are the reasons for re-referrals to [redacted] Psychology LD Team and [redacted] Psychology LD Team?  
 Ultimately, is the service delivered in the best possible way?

2 (c) In which ways do you think the audit will improve patient care / outcomes?

The outcomes of this evaluation will identify the referral patterns and weaknesses in referral processes, and provide further recommendations regarding the appropriate allocation of resources and referral processes. This should improve the efficacy of working across [redacted] LD Team and [redacted] LD Team?

3 (a) Type of Audit Please Tick ✓ where appropriate – more than one might apply

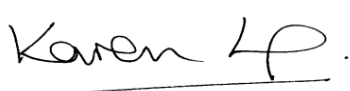
|                       |                          |                     |                          |               |                            |
|-----------------------|--------------------------|---------------------|--------------------------|---------------|----------------------------|
| (A) National          | <input type="checkbox"/> | Mandatory e.g. PEAT | <input type="checkbox"/> | Non-mandatory | X <input type="checkbox"/> |
| (B) Organisation-wide | <input type="checkbox"/> | Directorate based   | <input type="checkbox"/> | Team based    | X <input type="checkbox"/> |
| (C) Multidisciplinary | <input type="checkbox"/> | Uni-disciplinary    | <input type="checkbox"/> | Borough Led   | <input type="checkbox"/>   |
| (D) Multi-agency      | <input type="checkbox"/> |                     |                          |               |                            |

Other (please state):

|   |                          |                             |                          |                                   |                          |
|---|--------------------------|-----------------------------|--------------------------|-----------------------------------|--------------------------|
| 3 (b) Does your audit criteria apply to any of the following? If so Please Tick ✓ where appropriate   |                          |                             |                          |                                   |                          |
| NHS Litigation Authority (NHSLA)  | <input type="checkbox"/> | Care Quality Commission CQC | <input type="checkbox"/> | Risk Register                     | <input type="checkbox"/> |
| Organisational Policy   | <input type="checkbox"/> | [REDACTED]                  | <input type="checkbox"/> | Patient Survey                    | <input type="checkbox"/> |
| NICE guidance   | <input type="checkbox"/> | [REDACTED]                  | <input type="checkbox"/> | DH Policy Implementation Guidance | <input type="checkbox"/> |
| National audit  | <input type="checkbox"/> | Improving working lives     | <input type="checkbox"/> | Essence of Care                   | <input type="checkbox"/> |
| Other (please state, e.g. Issue of local concern):  |                          |                             |                          |                                   |                          |
|   |                          |                             |                          |                                   |                          |
| 4(a) Who will be on the audit steering group and what consideration has been given to the involvement of patients, carers or the public?<br>The focus of this service evaluation is the examination of the referral process therefore the clients' involvement is not required. However, the clinicians will be approached to gather information on their individual caseloads if required. |                          |                             |                          |                                   |                          |

|   |  |
|---|--|
| For more information on Information Governance, please contact:<br>Teresa Candfield or Marjan Daneshpour  |  |
| 5) Data Collection (please consider, and where possible answer all of the following questions)  |  |
| 5(a) Where from? Audit data can be collected from many sources including: medical records/RiO, nursing records, patients, clinicians, and other staff.  | RiO, allocation notes, PCNS clients database, clinicians |
| 5(b) How? The data source will obviously influence the method used to collect data. E.g. If data is to be collected from patients the most appropriate method might be a survey or interview. If data is to be collected from medical records, it will be necessary to design a data collection proforma. Questionnaires, one-to-one interview, focus groups. | Data Collection Form to be developed.                    |
| 5 (c) How much? As a guide, a sample should include a minimum of 30 cases and perhaps as many as 100. If the initial sample proves to be too small to provide data necessary, it can be added later.  | All referrals received within last 6 months              |
| 5 (d) Who? Who will be responsible for collecting the data? Ensure the person identified understands their role.  | Joanna Beckett (Clinical Psychologist, supervisor)       |
| 5(e) Timescale? Over what period is the data to be collected?   | May 2015 – August 2015                                   |
| 5 (f) Pilot Audit? Y/N In most cases it will be advisable to carry out a pilot to check quality of questionnaire, length of interview, etc. In light of the pilot audit findings, modifications to any of the above may need to be made. Smaller sample is appropriate for pilots.  | Y  |

|   |
|---|
| <p>6(a) Who may be affected by the outcomes of this Audit?<br/>The outcomes of this outfit will inform changes in the processes rather than individuals.</p>  |
| <p>6(b) With whom and where will the final report be shared? i.e Local service area governance committee, Integrated Governance Committee,<br/>Internally only. LD [REDACTED] Team and LD [REDACTED] Team</p>   |
| <p>6c) Who will take responsibility for disseminating the results of the audit and following through recommendations? And how and when will the recommendations be evaluated, monitored and reviewed?<br/>Names and role.<br/>Joanna Beckett to disseminate the results of the service evaluation and provide [REDACTED] and [REDACTED], the Joint Managers of [REDACTED] with the recommendations.</p> |
| <p>All completed audits must be followed up with a completed recommendations monitoring form, available on the "your health care" intranet site<br/><a href="#">LINK TO GO HERE</a></p>   |

|  |   |
|--|---|
| <p>7 Ethical Approval – if required please contact Maggie Elliott on:<br/><a href="mailto:Maggie.Elliott@stgeorges.nhs.uk">Maggie.Elliott@stgeorges.nhs.uk</a></p>   |   |
| <p>Ethics approval given by:</p> <p><u>Dr Karen Long</u></p>  <p><b>Date ethically approved:</b><br/><u>26 May 2015</u></p> | <p><input type="checkbox"/></p> <p><input type="checkbox"/> Name of possible committees that would give ethical to go here.</p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> |

|   |                          |
|---|--------------------------|
| <p><b>8 (a) For which of the following do you consider you may need assistance from the Quality, Assurance &amp; Governance Manager / Quality &amp; Audit Lead? – put your role first!!</b></p> |                          |
| Literature searches   | <input type="checkbox"/> |
| Developing standards  | <input type="checkbox"/> |
| Initial meetings  | <input type="checkbox"/> |
| Planning meetings   | <input type="checkbox"/> |

|  |                            |
|--|----------------------------|
| Questionnaire design                             | <input type="checkbox"/>   |
| Pilot  | <input type="checkbox"/>   |
| Amendments to questionnaire                      | <input type="checkbox"/>   |
| Data collection                                  | X <input type="checkbox"/> |
| Data analysis                                    | X <input type="checkbox"/> |
| Report writing                                   | <input type="checkbox"/>   |
| Presentation writing                             | <input type="checkbox"/>   |
| Presentation                                     | <input type="checkbox"/>   |
| Binding of report and distribution               | <input type="checkbox"/>   |
| Make recommendations for improvement             | <input type="checkbox"/>   |
| Other assistance (please state what you require) | <input type="checkbox"/>   |

## Appendix C. Focus group interviews – questions

### Your experience of processing NdS referrals

1. What is your experience of managing/coordinating the NdS referrals?
  - 1.1. How efficient do you think we are in processing the NdS referrals?
  - 1.2. Are the NdS referral routes clear to you? If not, why?
  - 1.3. From your experience, what are the most common reasons for the referrals being delayed?
  - 1.4. Were there any incidents of referrals being missed/lost? How did it happen?
  - 1.5. What does work well?
  - 1.6. What does not work?
  - 1.7. What could be improved?

### Your experience of using current NdS referral forms

1. What is your experience of using the NdS referral forms?
2. From your experience, are the information provided on the form sufficient to process the referrals accordingly? What is missing?
3. From your experience, do you get a clear picture of the reasons of referral? If not, why?
4. Do you feel that you can make an informed decision regarding the risk based upon the information included in the NdS referral forms? If not, why?
5. From your perspective, can you prioritize the referrals appropriately based upon the information included in the NdS forms?
6. Can the forms be be improved? If so, how?

## Appendix D. Final Template Analysis Form

### **1. Referral processes**

#### **1.1. Differences in referral processes between two teams**

1.1.1. Structure of the LD meetings

1.1.1.1. Referrers presence at the LD meetings

#### **1.2. Lack of clarity regarding referral processes**

1.2.1. Access to the \*\*\* service

1.2.2. Information about the \*\*\* service

1.2.3. Referral processes dependent upon individuals

#### **1.3. Improvement of referral processes**

1.3.1. Guidelines for team members

1.3.2. Role of admin and clinicians in processing the referrals

1.3.3. Single Point of Access

### **2. Referral Form**

2.1. Number of referrals forms

2.1.1. Confusion about the selection of the form

#### **2.2. The quality of information in referral forms**

2.2.1. Insufficient information

2.2.2. Difficulty understanding reasons for referrals

2.2.3. Risk

2.2.4. Consent

#### **2.3. Improvement of referral forms**

2.3.1. Number of referrals

2.3.2. Accessibility of the form

2.3.3. Information requested

**Appendix E. New referral form**

**\*\*\*\* SERVICES**

**Address** \*\*\*\*\*  
 Tel. No: \*\*\*\*\* Fax No: \*\*\*\*\* Email: \*\*\*\*\*  
 \*\*\*\*\*  
[www.\\*\\*\\*\\*\\*](http://www.*****)

REFERRAL FORM

Please indicate the nature of the referral:

LD       ASC       ADHD       Training       \*\*\*\*\*   
 Request

**Please attach any relevant documents, such as previous reports and assessments if available. We may request further information from you to process the referral accordingly.**

**The responsibility for this client rests with the referred/referring agency until the referral has been accepted in writing by \*\*\*\*\* Services.**

**Learning Disability (LD)** means that the person has substantial limitations in conceptual understanding, practical abilities and adaptive/social functioning. The following three criteria must be met for LD: significant impairment of intellectual functioning, significant impairment of adaptive/social functioning and age of onset before adulthood.

**Autism Spectrum Condition (ASC)** is a developmental condition characterized by deficits in language and communication, social understanding, social imagination. It is accompanied by a narrow and repetitive range of behaviours.

**Attention Deficit and Hyperactivity Disorder (ADHD)** is a group of symptoms that include inattentiveness, hyperactivity and impulsiveness.

\*\*\*\*\* – internal referrals only.

| For LD, ASC, ADHD and CNRT   |              |
|--|--------------|
| Client's Name:   | Male/Female: |
| Address:   | NHS no:      |
| GP Name:<br>GP Address:  |              |
| Reason for referral/Presenting problem: <i>(How long has it been an issue? How does it affect the person?)</i> |              |
| Relevant Information:<br>• <i>Current life context</i>   |              |

|   |  |
|---|--|
| <ul style="list-style-type: none"> <li>• <i>Medical and psychiatric conditions</i></li> <li>• <i>Professionals/services involved</i></li> <li>• <i>Does this person present <b>risk</b> to self <input type="checkbox"/> others <input type="checkbox"/> property <input type="checkbox"/></i><br/> <i>Please clarify:</i></li> </ul> |  |
| Has this person consented to this referral? Yes <input type="checkbox"/> No <input type="checkbox"/><br><i>If yes, how?</i><br><br><i>If no, why?</i>   |  |
| <b>For internal referrals only:</b> <ul style="list-style-type: none"> <li>• <i>Service/professionals required:</i></li> </ul>  |  |

|                                    |  |
|------------------------------------|--|
| <b>For Training Request</b>        |  |
| Name of service required training: |  |
| Details of training required:      |  |
| Expected number of attendees:      |  |
| Preferred venue:                   |  |

|                          |            |
|--------------------------|------------|
| <b>Name of referrer:</b> | Address:   |
| Job Title:               |            |
| Date:                    | Telephone: |

|  |
|--|
| <b>FOR INTERNAL USE ONLY</b><br>Date referral received:<br><br>Action/Referral forwarded onto: |
|--|



## **PART THREE: RESEARCH REPORT**

### **The Lived Experience of Receiving a Diagnosis of Asperger Syndrome in Adulthood.**

## **Abstract**

**Objective:** Research exploration of the experience of a diagnosis of Autism Spectrum Disorder (ASD) has largely examined parental responses. However, despite an increase in the early detection of ASD, there is a relatively high number of adults seeking a diagnosis. It is therefore important to understand the unique experience of receiving the ASD diagnosis late in life in order to facilitate the process of adjustment as well as to enhance positive outcomes.

**Methods:** Seven adults with a diagnosis of ASD were recruited from ASD Service in SE England. Semi-structured interviews were employed to acquire data that was subsequently analysed using Interpretative Phenomenological Analysis.

**Results:** Four super-ordinate themes were generated to illuminate the complexity of the experience of receiving Asperger Syndrome (AS) diagnosis: the struggles of being a misfit; revelation; realisation and making meaning of the self and AS; and the value and importance of support.

**Conclusion:** The findings of this study emphasise a key role of the AS diagnosis in the respondents' understanding of self and the past. Diagnosis was not self-threatening but can be a catalyst for change in those who were actively seeking AS diagnosis as potential explanation for enduring difficulties. The experience of receiving the AS diagnosis should not be considered a single event but process that encompasses reflections on the past, present and future that evokes a range of different emotions.

## 1. Introduction

### 1.1. Background and Rationale

Autism Spectrum Disorder (ASD) encompasses phenomena described as lifelong neurodevelopmental conditions characterised by persistent deficits in social communication, social interactions, and social imagination, and accompanied by restricted, repetitive patterns of behaviour, interests and/or activities (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, DSM-V). Although the diagnostic category of Asperger Syndrome (AS) was replaced by less confusing and overarching ASD, practitioners continue to use it to describe a specific behavioural profile. Thus, individuals with AS present with all the core ASD difficulties along with intense and all absorbing interests, intact verbal communication and average or above average intelligence.

A clinical diagnosis in childhood of a neurodevelopmental condition such as ASD or Attention Deficit Hyperactivity Disorder (ADHD) confers significant implications for children and carers beyond categorization of symptoms into a diagnostic class and treatment (Singh, 2011). Autism-related research has understandably privileged parental responses to their children's diagnosis of ASD revealing diverse and inconsistent reactions (Wachtel & Carter, 2008; Pakenham *et al.* 2003; Avdi *et al.* 2000; Midence & O'Neil, 1999). Parental sadness, shock, regret, anxiety and anger as well as confirmation, relief and celebration were amongst the most common parental experiences (Robinson, *et al.* 2014, Cridland *et al.* 2014, Mount & Dillon, 2014; Poslwasky *et al.* 2014).

Research has also elicited parental narratives of difficulties in establishing a child's diagnosis, dismissal of concerns about a child's development or behaviour, and families' perseverance (Robinson, *et al.* 2014). Such experiences are often construed within a 'stage framework' of parental adaptation to a diagnosis of AS encompassing: pre-diagnosis, diagnosis, post-diagnosis and acceptance (Mansell & Morris, 2004). Thus, in the pre-diagnosis stage, often lasting between 1 to more than 10 years (Howling & Moore, 1997), parents appear confronted by a sense of guilt and self-blame alongside family strains (Midence & O'Neil, 1999) or

frustrations caused by delays in obtaining the diagnosis (Howling & Moore, 1997). During the diagnosis stage some report shock and disbelief (Siegel, 1997) while others, relief (Midence & O'Neil, 1999). In the subsequent stage, parents may grieve for the 'hoped for' child and/or process the dissonance between their 'normal' appearance and disability (Midence & O'Neil, 1999). Through a final stage of acceptance and adaptation, parents process the positive and negative consequences of receiving a diagnosis, and may use it as a framework both to construe their child's behaviours and as a gateway to support.

Making sense of diagnosis of changed health status and illness has been increasingly researched over the last three decades, with diverse models utilized to encapsulate experiences and gain understanding of mechanisms of adjustment (Emanuel, *et al.* 2016; Brandao, 2015; Andrykowski, 2008). Notable amongst these have been models of bereavement (Maciejewski, 2007), transactional resource based models (Lazarus & Folkman, 1986) and more dynamic adjustment model by Charmaz (1995). Yet these models appear to delineate adaptation to illnesses that are often physical, progressive and diagnosed after a brief period of awareness of symptoms, and as such – very different to a diagnosis of ASD (Warren, 2009; Robinson *et al.* 2005). Thus, ASD is not progressive and there is no treatment, and those diagnosed with it experience symptoms throughout their lives although they have no insight into their causes (Punshon, *et al.* 2009). Furthermore, the clinical presentation of ASD is highly heterogeneous, may vary over time and is often exacerbated by comorbid psychiatric conditions.

While there is a substantial cadre of research capturing parental reactions to a child's diagnosis and adjustment to physical impairments, data on adults' reactions to their own diagnosis of ASD is scarce. Despite progress in the early detection of ASD, these highly heterogeneous neurodevelopmental conditions continue to impose diagnostic challenge and a relatively large proportion of individuals remain undiagnosed, misdiagnosed or diagnosed late in life. They often grow up misunderstood, bullied, with a sense of being different and not fitting in (Humphrey & Hebron, 2015; Balfe & Tanta, 2010). Indeed by the time they receive their diagnosis of a neurodevelopmental disorder, such as an autism

spectrum condition, many of them report severe depression, anxiety and express suicidal intent (Cassidy et al 2014; Ghazuiddin, 2005; Gillberg, 2002).

The importance of receiving an autism diagnosis in adulthood has already been recognised. Thus, NICE Guideline: Autism in adults – diagnosis and management (2012) specifies that the assessment feedback ‘should be individualised and consider involving a family member, partner, carer or advocate, where appropriate, to support the person and help explain the feedback. It also emphasises the significance of assisting an individual to recognise signs or symptoms with which they are experiencing difficulty. Yet there is no explicit guidance as to how this can be achieved, and service provision for adults with ASD in the UK is scarce. Given an imperative to include service users’ perspectives in care, the voice of adults with ASD should be considered when developing such services (World Health Organisation, 2012; Department of Health, 1999; Russell & Norwich, 2012; Moyes, 2003; Pakenham *et al.* 2003). The latter should also be informed by literature and extensive research. is

Nonetheless, there is only a few studies that explored adults’ experiences of their ASD diagnosis. Thus, Bargiela *et al.* (2016) addressed the diagnostic challenges imposed by ASD gender differences. The study was focused on the depiction of the female autism phenotype, its role in women’s experiences of diagnosis, misdiagnosis and missed diagnosis, and their way of coping with difficulties. It emphasised the phenomenon of camouflaging or pretending to be normal and internalisation of difficulties leading to a range of emotional strains. Most women welcomed their ASD diagnosis as it fostered their sense of belonging and promoted more positive sense of self. The findings of two further studies on the adults’ experience of an AS diagnosis by Punshon *et al.* (2009) and Powell & Acker (2016) pointed towards a mixture of positive and negative emotions. Both studies captured respondents’ sense of relief and an explanatory value of their diagnosis that was also depicted in an unpublished doctoral thesis by Cousins (2001). In addition to that, Powell & Acker (2016) delineated feelings of being blamed, scrutinised, or treated differently whilst Punshon *et al.* (2009) noted that the participants’ complex experience was affected by the beliefs of family, friends and wider society. Both Punshon *et al.* (2009) and Cousins (2001) highlighted the

negative life experiences prior to receiving a diagnosis of AS while Acker & Powell (2016) and Cousins emphasised the importance of post-diagnostic support.

Notwithstanding the insights these studies offer, they also present with some significant limitations. Cousins' self-selected sample comprised of individuals recruited online who identified themselves as having an ASD, who might or might not have a formal diagnosis of AS. The final sample of ten adults in the study by Punshon's *et al.* (2009) was not clearly defined. Also, the length of time between an interview and their diagnosis varied significantly between cases (3 months to 7 years), which may suggest that the participants were at different point of the adjustment process. Only adults actively psychotic or having an intellectual disability were excluded and there was no information on the prevalence of psychiatric comorbidities, which may have influence the results. The study by Powell & Acker (2016) captured an initial reaction only soon after the person received a diagnosis, which may have changed with time. It would also appear that all the published studies privileged the impact of diagnosis rather than the process of making sense of it, which is the focal point of current research.

This study is an attempt to boost an interest and stress the importance of researching the experience of a late diagnosis of ASD. Unlike the previous studies, the present research investigates a highly homogenous sample of both males and females with a formal diagnosis of AS and with no comorbidities that could significantly distort the results. It looks beyond the impact of the AS diagnosis and examines the meaning making and the essence of the experience of receiving and living with a diagnosis of AS.

## **1.2. Aims of the Current Research**

This research aims to explore and understand the experiences of a diagnosis of an ASD in adults. It attempts to investigate the manner in which adults make sense of their diagnosis, the way they conceptualise it within the context of their life experiences and identity. It is hoped that the knowledge gained through this research would inform the development of post-diagnostic adjustment programmes for adults with ASD.

## 2. Method

### 2.1. Design

Given the under-researched field of lived experience of diagnosis of ASD in adults, a qualitative approach was utilised to generate rich data that would provide an in-depth account of adults' experiences of their diagnosis of ASD.

Whilst there is a number of different qualitative approaches that could have been employed, Interpretative Phenomenological Analysis (IPA), that draws upon phenomenology, hermeneutics and idiography, was considered the most suitable and as such it informed both data collection and data analysis. Thus, unlike Grounded Theory that aims to generate theory through inductive examination of data (Lawrence, *et al.* 2013), IPA is not concerned about the formulation of objective depiction but exploration of participants' personal experience and understandings (Brocki & Wearden, 2006; Reid, *et al.*, 2005), and their subjective perceptions (Flowers, *et al.* 1999).

IPA was also more preferable than narrative analytic methods that are concerned with the narratives that people construct to bring order and meaning to an ever-changing world (Murray, 2008). The primary focus of this research was to capture the meaning and the essence of participants' experience rather than the manner in which the narrative is organised and structured. Given the nature of this research enquiry, Discourse Analysis was also considered unsuitable as it focuses on the function of language in the construction of social reality (Willig, 2009).

IPA allows an identification of both similarities and differences between respondents; it focuses on processes over time (Brocki & Weardern, 2006), complexity and personal nature of the issues (Kay & Kingston, 2001), and novelty (Smith & Osborn, 2003), which also warrants its application within this research.

Given IPA's phenomenological underpinning, it focuses on experience and individuals' personal understanding of their experience that the current research attempted to capture (Smith, Flowers and Larkin, 2009).

The idiographic nature of IPA also fits with the objective of this research, which is to explore and investigate the lived experiences of a small group of individuals. It examines individual perspective of each participant in an in-depth manner. This research is not concerned with generalisation of findings for larger population but understanding of the phenomena and the possible transferability from one group to another.

Moreover, hermeneutics as yet another theoretical underpinning of IPA, highlights the significance of an awareness of the researcher's own bias, presumptions and beliefs in the process of interpretation of data (Smith *et al.* 2009). The analytical process in IPA, often called a double hermeneutic, emphasise an active role of the researcher who attempts to make sense of the participants' meaning making (Smith & Osborn, 2008). This appeared to be particularly important within the context of this research due to the researcher's familiarity with the respondents and closeness to the researched subject.

IPA is theoretically rooted in critical realism and the social cognition paradigm (Smith *et al.* 1999). The former, adopted by the researcher, stresses the importance of meaning and context of the phenomena. Individuals may experience different parts of reality, and so, their meanings may differ. Based upon the social cognition paradigm these differences in meaning can be reflected in speech and behaviour. This study relied on the analysis of interviews to access and develop an understanding of these similarities and differences.

## **2.2. Quality Issues**

The quality issues relating to qualitative research were considered in line with criteria by Yardley (2000). These include: sensitivity to context, commitment and rigour, transparency and coherence and impact and importance.

First, the researcher met the sensitivity to context criteria through a review of the relevant literature and the context in which the study was conducted. Thus, the choice of semi-structured interview enabled participants to provide as much information they wished, and was subsequently analyzed in a reflective manner.



That is, the researcher paid particular attention to her own assumptions and pre-determined ideas while coding the transcripts. The researcher's supervisor offered further perspectives and possible interpretations that enabled the researcher to remain more open-minded. Furthermore, the researcher was particularly aware of potential power imbalance, particularly as she could be viewed as a gate keeper to the specialist services: participants were explicitly reassured that their views are important and will not influence service provision. The researcher also asked respondents to elaborate when their reports were somewhat vague or incomplete (Riessman, 1993).

Second, criteria to reassure that commitment and rigour were met, was evidenced through thoroughness in data collection, transcription, analysis and reporting. The researcher's commitment is also reflected in her intention to use the findings in order to inform both provision of post-diagnostic sessions and service development. The researcher followed the stages of IPA study in line with guidelines by Smith et al. (2009). Two of the transcripts along with initial codes and emerging themes and super-ordinate themes were scrutinised by the researcher's supervisors to ensure these were reflected in respondents' reports. Also, the super-ordinate themes were discussed with a practitioner psychologist specialising in ASD assessment and therapy, who has an extensive knowledge and experience of providing diagnostic assessments.

Third, the criterion of coherence was met through the selection of epistemological standpoint and methodology that reflects the research question. The researcher felt that IPA corresponds with her position of the critical realist that fits with the research aim to explore the lives experience. Transparency in the presentation of analysis was achieved through careful transcription and extracts from interviews that were used to support interpretations made by the researcher. The research procedures were also described in detail to add transparency. The researcher, given her epistemological position, remained reflective throughout the process to limit her influence of beliefs, intentions and assumptions on the data collection, interpretation and presentation.

Last, the criteria of impact and importance were considered when choosing the subject of this study and its utility. Thus, it was thought that researching the subject would enrich the understanding of the selected phenomena that is not well documented in the existing literature. In addition to the theoretical impact, this study was to inform the support provision and service development.

### **2.3. Researcher's Epistemological Position**

Since the current research aimed at capturing the respondents' experience, a critical realist epistemological stance was adopted. Particular attention was given to the researcher's reflexivity that was maintained throughout the research process (Appendix F).

### **2.4. Research Context**

The research was conducted in an ASD service covering two boroughs of London. This service provides both specialist diagnostic assessments of ASD and psychological interventions to adults with ASD and is a part of a larger neurodevelopmental service. The ASD assessments are undertaken by clinical psychologists trained to administer diagnostic tools that are considered gold standard by NICE Guidelines (2012). These include: DISCO and/or ADI-R and ADOS-2.

Referrals for assessments are expedited through a number of pathways that include: self-referrals, GP referrals and referrals from psychiatry and secondary care. Depending on clients' presentation, the assessment process may take between two to six sessions. There are followed by additional post-diagnostic sessions if the diagnosis of ASD is confirmed and upon clients' agreement.

### **2.5. Respondents**

In the attempt to obtain rich data that would allow a thorough and in-depth analysis leading to the development of meaningful themes both within and between respondents, the sample size should correspond with a number of

interviews of between four and ten. It was expected to recruit no more than eight respondents for single interviews.

### **2.5.1. Inclusion/Exclusion Criteria**

Respondents were purposefully sampled from the clients who underwent their diagnostic assessments in the specialist ASD service. The recruitment was guided by the following criteria:

Inclusion criteria:

1. Individuals aged over 18.
2. Have a diagnosis of Autism Spectrum Condition that is best described as Asperger Syndrome.
3. Have been diagnosed aged 18 or above at the time of diagnosis.
4. Have been diagnosed no longer than two years prior to the date of the interview.
5. Able to participate in the interview verbally and in English.
6. Male or female.

Exclusion criteria:

1. Aged under 18.
2. No diagnosis of Autism Spectrum Condition/Asperger Syndrome.
3. Diagnosis of ASD received before the age of 18.
4. Diagnosis of ASD received longer than 2 years ago from the time of the interview.
5. Unable to participate in the interview verbally or in English.
6. Have a diagnosis of Learning Disability, ADHD and/or Personality Disorders.
7. Present with a significant impairment in the domain of social communication.

## 2.5.2. Final Sample

The final sample comprised of seven respondents (see Table 6). Their names have been changed for reasons of confidentiality. Also, to protect the respondents' identity, the characteristic of the sample are not described in detailed.

| Respondent | Age at time of interview (years) | Education    | Employment   | Marital Status |
|------------|----------------------------------|--------------|--|----------------|
| Monica     | 35 - 40                          | Postgraduate | Full-time employment in the past/currently unemployed        | Married        |
| Lukas      | 44 - 50                          | Postgraduate | Full-time employment   | Married        |
| Crystal    | 37 – 43                          | Postgraduate | Full-time employment in the past/currently working part-time | Married        |
| Zara       | 30 – 35                          | Postgraduate | Full-time employment in the past/currently working part-time | Married        |
| Mike       | 44 - 50                          | Postgraduate | Full-time employment in the past/currently unemployed        | Single         |
| Samantha   | 37 - 40                          | NVQ          | Full-time employment in the past/currently unemployed        | Cohabiting     |
| Nathan     | 30 - 36                          | Postgraduate | Full-time employment in the past/currently working part-time | Single         |

**Table 6. Characteristics of the sample.**

Thus, the final sample comprised of four women and three men, ranging in age from 30 to 46 years (mean = 38). All respondents but one were of British origin.

All were diagnosed with Asperger Syndrome at the ASD service between 2014 and 2016. Their educational level ranged from vocational qualification to postgraduate degrees, with the majority having the latter. Three respondents were in employment and all had the history of either full or part-time employment at the time of this research. Five of them were either married or cohabitating and two had children with ASD.

## **2.6. Materials**

The semi-structured interview schedule was developed to prompt respondents to describe their experiences (Appendix H). This method is considered to be appropriate for an IPA study as it facilitates a conversation and enables to probe and explore particular areas of interest. The interview was developed in line with the guidance by Smith, Flowers and Larkin (2009) and with further support from an expert in ASD (Counselling Psychologist).

The schedule covered the areas that were relevant to the research question, that is, how respondents reacted to the confirmation of their ASD diagnosis and what meaning they ascribed to the novel information. The questions were open-ended in order to elicit narratives but probing questions were also used to help respondents articulate their experiences. Since the interview schedule was successfully applied in the first interview and allowed to obtain a rich account, it remained largely unchanged and was used in all further interviews. Only prompt questions were added and used when needed to clarify the open-ended questions.

## **2.7. Procedures**

### **2.7.1. Ethical Approval**

Following minor alterations to the Participant Information Sheet, the research proposal was also approved by the Ethics Committee for Psychology at the University of Leicester in April 2017. Since the participants were not recruited from the NHS trusts but a social enterprise, the proposal required to be approved by the SW London Clinical Governance. The permission from the SW London Clinical Governance was granted in September 2016 (Appendix I - K).

### **2.7.2. Recruitment**

Letters that included the Participant Information Sheet (Appendix L) and Consent Form (Appendix M) were sent to a pool of eleven clients selected from a client database following application of inclusion and exclusion criteria. Seven consent forms were returned and those clients were invited for an interview. Prior to the interview, the purpose of the research and methodology were explained to clients verbally allowing them to ask questions. They were reminded of their right to withdraw from the project at any time without giving a reason as well as confidentiality and anonymity.

Immediately after the interviews, respondents had the opportunity to discuss the potential impact of the interview on them. None of the respondents indicated that they were subject to undue stress. Nonetheless, they were reminded of their right to contact the researcher should they want to discuss the aroused emotions or research project itself.

Of importance is fact that the research sample was recruited from the service where the researcher was employed. Therefore, the emphasis was placed on clients' understanding of their voluntary participation that would not have any implication on their ability to access services in future. The respondents were also recruited amongst clients who were no longer open to the ASD service.

It was thought that clients' familiarity with the researcher would help respondents to engage with the research process and facilitate an open dialogue. Furthermore, the researcher's expertise in the area of ASD enabled her to structure and pace the interview as well as prepare the environment that meets specific needs of this population. Also, the researcher was in the position to offer specialist support should the respondent find the process stressful or anxiety provoking.

### **2.7.3. Qualitative Interviews**

All interviews were conducted at the ASD service. Interviews lasted between 45 and 70 minutes and were audio recorded and subsequently transcribed verbatim.

The process of transcription allowed the researcher to become familiar with the data. All identifying information was removed or changed to conceal the identity of the respondents.

## **2.8. Analysis**

IPA was considered the most suitable methodology for this study and so the data analysis process followed its principles, as detailed by Smith and Osborn (2008). Transcripts were first read individually allowing the researcher to familiarize herself with each account. Initial ideas were noted on the right hand of the transcript while reflective notes were recorded to aid the recall. On the left side of the transcript researcher listed emerging themes based upon the connections between ideas within and across cases. Following that, all the themes were analysed for relationships and similarities across transcripts creating clusters of themes. These were subsequently titled producing superordinate themes. The superordinate themes were being verified through re-reading the individual transcripts to ensure that they reflected the accounts provided by the respondents. As a result, a table of superordinate themes along with associated sub-themes and supporting verbatim text extracts was generated.

## **3. Results**

This section presents the results emerging from the seven participants' accounts of their experience of receiving a diagnosis of Asperger Syndrome.

The analysis of rich data collated in semi-structured interviews revealed four super-ordinate themes that are shown in Table 1. These themes do not reflect every aspect of the adults' experience of receiving diagnosis of AS. They are selected given the frequency of their occurrence and relevance to the research question posed by the researcher engaged in a double hermeneutic process (Smith, Flowers & Larkin, 2009), that is – in the process of making sense of the respondents making sense of their experiences (Appendix N). As such, this account is subjective and may reflect some but not all facets of the respondents' experience.

| Super-ordinate Themes  | Subordinate Themes  |
|--|---|
| <p><b>The struggles of being a misfit</b></p> <p><i>I do not fit in anywhere.</i></p>                          | <p>Sense of being different/not fitting in</p> <p>Pretending to be normal</p> <p>Masking difficulties</p> <p>Struggles and suffering</p>  |
| <p><b>Revelation</b></p> <p><i>I've found my tribe.</i></p>  | <p>Self-discovery and need of certainty</p> <p>Explanation</p> <p>Relief</p> <p>Hope for change</p>   |
| <p><b>Realisation: making meaning of the self and AS</b></p> <p><i>I'm getting to know me and my life.</i></p> | <p>Mixed feelings and confusion</p> <p>Self-understanding</p> <p>Self-acceptance</p> <p>Disclosure and Stigma</p> <p>Late diagnosis</p> <p>Identity</p> <p>AS symptoms management</p> |
| <p><b>The value and importance of support</b></p> <p><i>I can't do it without support.</i></p>                 | <p>Support from family and friends</p> <p>Service Provision</p>   |

**Table 7. Super-ordinate and subordinate themes**

The analysis of data explicitly shows the complexity of respondents' experience of receiving the diagnosis of AS. As such, it does not begin and end at the time of obtaining official diagnosis (i.e. feedback session) but stretches far beyond that precise moment in time. In all but one cases the respondents' accounts illustrated their struggle and suffering prior to their diagnosis, their sense of being different and not fitting in, their first encounter with AS as a condition, their identification with it, confirmation of diagnosis and the process of making sense of their diagnosis, and its impact on their lives and sense of identity.

The super-ordinate themes were used to structure the results section below.

### **The struggles of being a misfit**

This super-ordinate theme reflects expressions of struggle and difficulties experienced by the respondents throughout their lives. Six of seven reported a clear sense of being different and not fitting in within their social context prior to



their diagnosis of AS. Their accounts indicated clear distress compounded by their lack of understanding of reasons of their difficulties and attempts to hide them.

### ***Sense of being different***

Six respondents referring to their awareness of being different noted its emergence in early childhood through comparing themselves to their peers and concluded that they did not fit in and/or there were just different to others.

Samantha explicitly described her sense of being different:

*'I always knew that I was different from other people when I was younger, but I tried to hide it because I wanted to fit in with people'.*

Others articulated similar experiences of being not only different but also somewhat 'faulty'.

*'I always felt wrong. There is no other word for it. Just wrong'.* (Monica)

*'Before I had always felt that I was doing things wrong, or that I just wasn't getting it. I thought that maybe I was just dense. I just didn't know why I just didn't seem to get things the way that other people got them'.* (Crystal)

### ***Pretending to be normal and masking difficulties***

Without an understanding of the reasons of their sense of being different, all six attempted to either pretend to be normal, put more pressure on themselves to be like everyone else or simply mask their difficulties.

*'I think I had spent most of my life desperately trying to be normal and trying to fit in'.* (Monica)

Social mimicry was not exclusive to female participants but appeared particularly noted by them. They clearly described their efforts to look and act like others as if they were ashamed of being who they were.

*'I think that's something that I've noticed that I did a lot; I would just fake it to blend in with everybody... I've struggled and been on the verge of suicide wondering why I can't be that normal person. I would think that if I looked like this or dressed like this that I could be this normal person, I could be outgoing or loud or friendly'. (Samantha)*

Sustained attempts to mimic others left them feeling lost and confused. They questioned their identity and relied on others views and opinion when navigating through life.

*'I think my sense of self was so undefined, it was so like vapour. I would talk to one friend and I'd be so upset, and then I'd talk to [name] for support for an idea and she would have her opinion, and then I'd turn to Vicky and it would be slightly different, and then I'd go to that person and it'd be totally different. I was just like "stuck" in this haze, and I couldn't average out what the answer was'. (Zara)*

Crystal also wondered whether she had managed to convince others about being normal and subsequently depriving herself from the opportunity to be seen as her true self.

*'Sometimes I wonder if I've hurt myself, by working so hard to be so normal for so long... that I've kind of convinced others that I am'.*

Respondents perceived themselves as different and often tended to make themselves accountable for their struggles.

*'I think I had always very much felt that it was my fault. I felt that if I could just behave differently and be like everyone else then this wouldn't be a problem'. (Crystal)*

*'I was constantly riling at myself before, why can't you learn? Why are you such an idiot?'* (Lukas)

### ***Struggles and suffering***

Six of seven respondents described the struggle and suffering they have experienced throughout years, across different aspects of life at different life stages. Despite their belief in their own cognitive abilities, they experienced failure at school and work. They felt exhausted. Their sense of difference without understanding or attributing reasons was expressed as a source of particularly vulnerability amongst their peers.

*'You get bullied because of the effects [of AS], and because you are frustrated because you haven't had a diagnosis. The bullying in itself is so hurtful that this pushes you back into yourself, when you are already there anyway. It's all contributory factors that make it worse... That would have continued for me, I would have continued to lose jobs and friendships, and burn bridges with others. As I got older, I don't know what the result of that would've been... but basically, I didn't have a life at all. Therefore, I didn't have any hope and I wasn't getting stability in a professional sense, which meant that I wasn't on a steady income, and I suffered from the effects... I was continually losing work'. (Mike)*

*'I pushed myself thinking that if I push myself hard enough I will overcome what I didn't know then was symptoms of my disability. It was exhausting'. (Lukas)*

Respondents reflected on often unhelpful ways of dealing with the daily challenges they were facing, either at work or home.

*'Well erratic is a bit too strong of a word...but I mean my confusion, my permanent stress and confusion...my permanent tension. I mean I have been able to go through life with success and failures, success and failure, because I didn't really know how to solve the problems of living life. Say, I mean I had a constant sleeping problem which I tackled by drinking heavily and going to bed extremely late so I would sleep, but I was constantly tired'. (Lukas)*

*'I drank and really abused my body with alcohol for a long time... I was so frightened from an early age. I was told that I had to be social, I had to go out and be around people and be this person. I'd be downing shots just to get me*

*through. As I said, I understand realistically you can't segregate from people but I find it so hard to just sit and be around people, and just knowing that it's not me. I sat in a job for 10 years, when I did the hairdressing. I freaked out that day and walked out because I couldn't cope with the touching people, having to cuddle and kiss clients and shake people's hands, but I just dealt with it... I don't even know how the fuck I did that job, how I spoke to people and touched them'.*  
(Samantha)

Confusion and feelings of marked inadequacy were associated with experiences of low mood and anxiety. Respondents reported struggles, perceived defectiveness and ascribed responsibility leading to a range of diagnostic labels with which they were described: Depression and Anxiety (all) Borderline Personality Disorder and Eating Disorder (Samantha), Obsessive Compulsive Disorder (Zara) and Insomnia (Nathan). All respondents felt that prescribed diagnostic parameters did not fit their true self.

*'I had gone to various people, not knowing what was going on in my head. Knowing that things weren't right, and getting various different diagnoses'.*  
(Mike)

*'When I was going through the group, I noticed that there was no improvement in me. When people would talk about the things that would bother them, I wouldn't fit in with them. They didn't understand me when I said certain things... The more it went on, the more I was thinking - this just isn't right, this isn't helping me. I'm coming in here and I'm faking who I am again'.* (Samantha)

Respondents' sense that diagnostic labels did not fit their experience, appeared to engender disappointment with health professionals with whom respondents worked, and who were felt to fail them with no explanations to clarify struggles and suffering.

*'How come I spent so many years of my life in and out of counselling and therapy and no one noticed. The therapist I saw in [country] up until 1992, I can forgive her. I mean she was very famous and very, very, very good, but that was about the*

*time that Asperger's for adults was starting being discovered. I mean, she could have seen something. Then in [country] we saw a very famous psychiatrist and he didn't see. In the [country] I saw a counsellor for 6 years and she didn't see. Then I saw a counsellor here for a year or so'. (Lukas)*

## **Revelation**

### ***Self-discovery and need of certainty***

All respondents described the manner in which they became aware of the existence of AS. Key moments of revelation were described, such as reading a book or listening to a radio programme about AS, and noting their similarities to those with describing AS. In one case, a respondent's partner explicitly prompted him to consider AS as an explanation of his behaviours. Respondents identified themselves as sharing an AS profile, prompting requests of specialist ASD assessments. Only one respondent was referred for the assessment by another health professional.

*'For me it was actually a radio programme on Radio 2. I mean I almost didn't really notice because it was incidental. It's had happened before, where something ticked boxes, but this seemed to just tick all the boxes for me. To the point where I thought, oh this might be it'. (Mike)*

*'The first time I thought about it I think was when I had read the Curious Incident of the Dog in the Night Time'. (Crystal)*

*'It was my wife that realised it. She had been listening to podcasts and reading articles and thought - maybe this is by husband, this is what is ailing my husband'. (Lukas)*

Monica and Zara, both mothers of children with ASD described the similarities they started noticing between them and their diagnosed autistic children.

*'I think the biggest realisation was when the Educational Psychologist suggested it for my then daughter, [name]. When she sort of said about it and she was describing autism in girls and how it kind of goes wrong at that transition point,*

*at secondary age, it kind of dawned on me... So, I bought a book Autism in Girls, I think it was called'. (Monica)*

Six respondents initially tentatively, and then with more certainty and focused attention, compared their characteristics and behaviour with the AS profile, with increasing conviction felt that AS might explain their enduring difficulties.

*'And I started reading about it more. I saw poor handling of money, being very focussed, not being very social... but when I did the online test myself I started seeing well this looks very likely that I am on the spectrum.'* (Lukas)

*'I read it and literally as I read it, first of all [name/daughter] was coming straight through the pages, and also me. As much as I knew it was her, I knew it was me as well'. (Monica)*

*'I knew very quickly having started to read these anecdotes that everything about me made sense'. (Zara)*

Only Nathan, who did not himself seek AS diagnosis, actively decided not to research the condition. He explained that he was concerned that acquiring knowledge prior to his assessment could affect his behaviour during the assessment and either amplify or diminish certain traits and characteristics to either show bigger discrepancy or consistency with the AS profile.

*'No I didn't do any additional reading, apart from literally being sent through for assessment. I had known a few people with diagnosis, but I felt based on that that I knew as much as I would need going into it because everyone else would know enough. Also, as it's an assessment any sort of awareness of what they are looking for may have led me to either play up or play down depending on what sort of influence there had been'. (Nathan)*

Despite the majority of respondents' strong identification with the AS profile, they felt that their self-discovery needed validation. They were fearful that a

potential sense of belonging might be disconfirmed or denied due to their previous lack of fit.

*'There was that part of me that was so scared, thinking maybe these aren't your people and these aren't your tribe (laughs). You think that you'd found them, but you haven't. You're not one of them, when it just seemed so like I was. I guess I got scared to invest a lot in something, I feel like so many things in my life have been failures when I'd be so sure that they would work. You know, I'd been sure that I'd work this time or I'd fit in this time, but it always seemed like it or I didn't. Things always seem to fall apart, and I was scared that this would be one more thing that was going to fall apart again.'* (Crystal)

### ***Explanation, Relief and Hope for Change***

All but one respondent described a sense of relief in response to the confirmation of AS diagnosis. The diagnosis was described as transforming with feelings of shame able to be externalised; they were no longer responsible for being different. Respondents described a sense of belonging for first time and no longer alone.

*'Oh I remember it very strongly. It was, I think I physically sank down a bit in relief because it gave an explanation to what had gone before. That was a big relief, because I knew that it was...not that I was not responsible for the mistakes of my past, I am still responsible for them; but it had an explanation why. Why are you such an idiot? Now I understand that it's not that I'm an idiot, but that the tools for dealing with these issues are just not there. Well they are, but not in the neuro-typical way'.* (Lukas)

*'You just know that you're not going mad. I had a feeling of elation... real elation...it was a relief to me that there was an explanation. All of a sudden there was a weight lifted off my shoulders, because the majority of things I have struggled through suddenly weren't all my fault.'* (Mike)

Within the context of new understanding of the cause of their difficulties, their sense of pre-diagnostic shame became particularly accentuated. They were both aware and ashamed of being different and therefore tried to conceal it.

*'Sometimes it [the AS diagnosis] has allowed me to not feel as guilty.'* (Monica)

*'It was like someone had taken away the guilt, I wasn't doing it [making life difficult for herself] on purpose anymore.'* (Crystal)

It seemed that the externalisation of shame amplified their hope to be able to be who they truly were as well as the hope that the façade that they generated to fit might finally disappear.

*'I feel like I want to stop that fight and pretending now, now that I know I can stop pretending and stop fighting, and just be me and relax and sort some stuff out.'* (Crystal)

Only one respondent, who felt he reflected less on difficulties, did not research or seek the AS diagnosis reacted to his AS diagnosis with disbelief. Nathan wondered whether the assessment was somewhat erroneous or based upon his potentially 'dishonest' reports. He doubted the assessment process and its subjective nature.

*'I was pretty dubious to be honest. I wasn't sure if there had been some sort of mistake or if I had, not given dishonest feedback...but done something against what I would've really have said/done that might've influenced it.'*

Nonetheless, in majority the confirmation of the AS diagnosis gave them hope for their lives to change and to move beyond confusion, for their true self to emerge within the newly found parameters.

*'I was like - great, now I can start and move forward, and I guess I kind of imagined that there would be one fix for it all. I kind of thought "oh great, now I've been diagnosed I can go and get it all fixed'.* (Mike)



### **Realisation: making meaning of AS and the self**

Initial elation and relief in response to the revelation or confirmation of their suspicion was followed by more focused and directed revisions, revaluations and reappraisals of past experiences, the AS itself and its relation to the self. All but one respondents delineated the efforts they put in the process of making sense of their diagnosis. They collated further information on AS through further reading, attending talks and/or support groups.

*'Quite rapidly there was a kind of thought of - oh, well I've been given that and that's for me. I'm going to spend a really long time working out how I feel about that'. (Zara)*

*'It [the diagnosis] does make you think about so many things, and it makes you realise so many things, and you can't help but think about the past'. (Monica)*

Despite researching the subject previously, the narratives illustrated their very individual engagement in the quest for meaning that seemed both confusing and illuminating.

*'Then, I went into a period of uncertainty as to what exactly Autism is, and I found wherever I looked and whoever I asked... There was never really a black and white answer. That caused a bit more confusion for me. I spent all my time reflecting, retrospectively and pulling it apart, which I always have done... but it was without a direction. Now, I had a direction to focus this on. I kept thinking that maybe I was crazy, and all the things going on in my head were ramblings. I had to kind of try and find a way to work out if I was right, and get an insight into how I was and how autism has affected me'. (Mike)*

Despite Nathan's apprehension to his diagnosis, he also engaged in the process of re-appraising his past experience from a new standpoint. However, his 'meaning making' seemed less systematic, rich and was tentative.

*'This might be why things happened in a certain way'.*

There was no one prescribed way of processing the received diagnosis and its relation to the self. The diagnosis meant change, although it was not clear at this point what this change would entail.

*'Nothing's changed... but everything has'.* (Monica)

### ***Late diagnosis***

All but one respondent reflected on the age at which diagnosis had been received, describing anger, sadness, resentment, despair and regret for the lost time. Respondents wondered how their life would have been different if they had been diagnosed earlier.

*'The despair how would life have looked if I had been diagnosed before'.* (Lukas)

*'Then I think the more realisation comes as you look back at things in the past that have gone wrong, and there is a sadness about it. There is sadness that if someone had realised when I was 7, then maybe my life would be very different now, if I had different support when I was younger. Sometimes there is a bit of an anger about that, there was a bit of an anger, especially when you got it so quickly'.* (Monica)

Crystal reflected on the support and assistance children with ASD are provided with; the support that she felt might have changed her life.

*'I suppose it's not really the anger in me, but more like jealousy; when I see reports of children with autism in amazing schools and camps and they can wear headphones to keep the noise out. You think that well they are getting a lot of help... but what about me? I guess later on I did have some anger. All these years that I could have known, and someone could've helped me... something could have been different. It just felt so late, to come now when my life is half over'.* (Crystal)

### ***Self-understanding, self-acceptance and identity***

The respondents' narratives clearly illustrated changes in their approach to the self, in the main reporting better understanding of themselves permitting a greater degree of self-acceptance.

*'I'm much more focussed, focussed. I am much more comfortable in my own body...in my own life...in my situation. I think what has happened is that the Autism has helped me to actually grow up and mature. I will probably think of something I should've later, but I feel it easier to grow now. Yeah, okay I'm using a cliché here but being on the spectrum and trying to live as a neuro-typical is like forcing a square peg into a round hole. Being on the spectrum, you can fit a square peg in a square hole, maybe that is one way of putting it'. (Lukas)*

A growing understanding of the reasons for past difficulties allowed expressions of greater self-kindness contrasting with frustration and self-excoriation of the past.

*'I think that I have to accept that that's who I am and that I have limits. That was my limit, but I did the best I could. I guess I'm gentler with myself a bit, more so than I have been in the past'. (Crystal)*

*'I don't feel that I have to try and keep up with everyone all the time'. (Monica)*

All respondents also reflected on the impact of AS on their sense of identity, and that the diagnosis of AS accelerated their self-development. Interestingly, there were some significant differences in the manner they conceptualised the relation between the self and AS.

Monica, Mike and Zara perceived AS as an integral part of their identity. It enabled them not only to feel 'whole' but provided solid fundamentals for growth. They felt 'unstuck' and no longer held back by an indefinable and incomprehensible reason.

*'My autism isn't an add-on to me, it isn't just a little that bolt- on, it is you- it has to be. I know there is this whole thing about "how people define themselves" and some people say, "oh you should say child 'with' autism" as if it's just part of them, whereas to me that's just rubbish. If you are autistic, you are autistic... It is at the core of your being'. (Monica)*

*'I felt like it gave me a missing part of my identity. It meant from that point, the rest of me has been able to grow. I have the key to understanding my real strengths and weaknesses. That's all I really ever needed I think, to feel...whole'. (Zara)*

Nonetheless, for Nathan the differentiation between the self and AS seemed to be rather confusing as he wondered whether some of his behaviours might be potentially explained by personal preferences rather than AS. He doubted his own personal agency and questioned if the diagnosis itself might licence certain behaviours and, for instance, cause him to 'be even more sort of adverse to social occasions'. Interestingly, Crystal and Monica also referred to the possibility of perceiving their diagnosis as 'an excuse' and wondered if others might see them as using it to their advantage.

*'It's the extent of how much stuff is truly my characteristics and beliefs and whatever, and what isn't. The only thing that makes that an unfavourable activity is because according to what you have been told, you're adverse to this certain thing. This is opposed to thinking well maybe I just don't like these people or that place or that sort of thing'. (Nathan)*

*'I use it as a reason when it's appropriate, as in if it's appropriate if it is the reason. It's not an excuse, but I can understand people might make it that way, but I don't want to. It just does most of the time explain things'. (Monica)*

For Crystal, however, the initial elation and hope in response to the AS diagnosis seemed to evaporate leaving her with the same sense of pretending and not being herself that she felt throughout her life.

*'I feel like it was such a new understanding of myself that I could stop fighting and pretending...at least that's what I thought at first, that I could just stop the fighting and pretending and just be me. Now I think "no, I'm still pretending... I'm still not being me", but I'm not sure when that me is going to appear. I feel like there was this door that was opened, but then it sort-of closed. Every day is that same struggle and that nothing is going to change, and in a way...it took away hope'. (Crystal)*

### ***Disclosure and Stigma***

The respondents' quest for meaning did not occur in a vacuum; it was not an insular or isolated process but one deeply interwoven with the very fabric of societal beliefs and norms. There was the meaning they ascribed to their diagnosis that they found validating and legitimising, and the fear that the society would not see it the same way. The disclosure itself made their condition 'public' and the public response was beyond their control.

*'It was [The diagnosis] private but public. To me, it was kind of saying that word and actually saying it out loud. Some people you say it to and they are just like - what does that mean but for certain people it really helps, it really helps to tell them'. (Monica)*

*'There is that thing saying that you are now officially different and that you do have a label. I think just thinking about it in a practical sense, what did become an issue for me was when you start to fill out forms of mental illness and disability'. (Mike)*

Although the actual reactions to their disclosures were largely positive, the respondents worried about being stigmatized or discriminated, particularly within the context of their employment. They seemed to consider potential costs and benefits of revealing a diagnosis and were circumspect about whom they told.

*'I try to tell people when it is convenient or necessary, I try and tell them that I am on the spectrum, I suppose that helps. Also, when I do or say something odd, they know'. (Lukas)*

*'As I said, someone who I know I haven't told them my diagnosis because I know they wouldn't understand it and they would judge me'. (Samantha)*

In case of Crystal it was indifference and dismissal with which she found difficult to cope: relatives were disinterested in AS and friends seemed not to perceive it as 'a big thing', which was somewhat invalidating.

*'My friends have said - oh well you don't like really have it... you can't be that autistic... you're normal... you're not weird. She's [mother] seen how much I've struggled for so long, and she says, oh I can see how you're kind of or a bit like that, but I don't think that anybody really thinks that I am. To me, I think that I am. I don't think that I'm - a bit like that, I feel like I actually have it'.*

Nathan, on the other hand, reported that some of his friends 'discredited' or 'denied' his diagnosis leading him to confusion.

*'I say I've still got that sort-of problem with being able to convince other people of it, I suppose I've come to accept it. I think there has only been about 5 or 6 people I have directly mentioned it to, and about 2 of those didn't really... Well I think my previous cynicism about this sort of thing, I think they were agreeing with that. At least two people had sort of denied it or discredited it and said - yeah... probably no; so there's that'. (Nathan).*

### ***Management of symptoms***

Respondents' accounts clearly illustrated their attempts to integrate their knowledge and understanding of AS into daily life. They described specific examples of situations that they started approaching differently. It transpired that the AS diagnosis allowed them to adjust their environments or behaviours in order to complete day-to-day tasks more effectively. They were able to pace themselves

and give themselves time to recover after participating in events that might deplete their emotional resources.

*'Sometimes you can genuinely say to yourself - it's okay... that's just too much. Also, the other thing I have realised, when I have had to things that are beyond my comfort level, it's allowing myself that time to recover. Whereas before I felt - everyone does all this stuff, suddenly I kind of realised that not everyone processes it in the way I do, and it's okay to need that break afterwards. If I don't have that break then I know it becomes too much'. (Monica)*

Similarly, Zara described her newly developed ability to plan and recognise the difficulties she might be facing, and so, prepare herself accordingly. They were no longer 'lost' but now had a framework within which they could understand their difficulties and use that newly acquired knowledge in their day to day lives.

*'I can better plan, I can recognise things are going to be hard and I can arrange my day or week or my environment, to make this easier on myself. Or, I'll be honest... there are times when I just have to accept that this is going to wreck me, but I haven't got any choice right now'.*

Six of seven respondents described diverse change they made through the application of their knowledge and understanding of AS, but the narrative of one of the respondents also implied a sense of disappointment and hopelessness. The initial expectation that an AS diagnosis would resolve problems and bring the opportunity for growth and positive change was not experienced as wished. AS, initially seen as the ultimate solution and the answer did not live up to its promise.

*'This isn't something I'm going to get better from... there is no cure. I think that's the hard part, knowing what to do with it. I don't know how to live my life any better, and I hoped I would. I hoped this knowledge would somehow give me the ability...of course the knowledge itself can't do that. I just wish that I could use the knowledge in some way to develop the skills to cope better, and get through days better, even practical things. That's hard. That I feel a bit stuck. I guess that*

*I've lost that feeling of hope that something would change or something good would happen'. (Crystal)*

Despite initial revelation, meaning making was not restricted to a single event but involves continuing emotional and cognitive shifts. As such the respondents' concept of AS might be dynamic and fluid, and continue to evolve in reciprocity with other life experiences.

*'Well that's the thing, on a really good day I see Autism as really positive. I see it as it makes me "me"; it makes me diligent, it makes me focussed, it makes me that sort of intelligent intensity of I can just sort of get down with things, and I like that part of it. Then, other days when I'm really struggling, especially socially or really struggling with anxiety, there are times that I just wish I wasn't...I just wish I was more normal, whatever that is. I think I kin of waver between condition and disorder. Some days it is a condition, and some days it is a disorder. When you can't manage social situations, it does feel genuinely disabling. Other times, it's just me and it just explains who I am, and that's fine'. (Monica)*

*'I think it just sort of changed depending on the day too...I guess it was more just if I was having a good day then I'd be thinking that I felt more hopeful today. I think it just depended a lot on circumstance during the day'. (Crystal)*

## **The value and importance of support**

### ***Support from family and friends***

All but one respondent referred to the importance of support from family and friends, irrespective of whether they felt it had been overtly offered. Those, who received some help from their families/friends perceived it as an essential resource. Those, who hoped to receive it but did not, articulated their disappointment.



*'The thing is, it's sounds awful but if my family were wiped out tomorrow in an accident, I wouldn't manage. I manage because I have Graham and he's always been my kind of support. I know without him I wouldn't cope, at all'. (Monica)*

*'As an adult, it does feel like you are very much on your own and so I think it is different. You might need someone who can take the place of what that parent would've done. I think I thought that my solutions. You know like now we know about this, how are we going to... But really no one is interested'. (Crystal)*

Zara, when asked what she would say to someone who was recently diagnosed, indicated the importance of having the right support network.

*'I would say "find people that can help you hold up a really positive mirror to what your strengths are, focus on those things in life. I would say, making sure you have people that can help you to see your positives is probably the absolute primary step'.*

Of interest, only three out of six respondents, who assigned value to the support provided by family/friends, indicated that the support had been offered to them. Two respondents sought counselling and found it very helpful in the process of making sense of AS and self. Crystal felt that she did not receive any support report from neither family/friends nor professionals. Her report clearly articulated her struggles to make desirable changes within her life and the self.

*'I think that they think - just get over it. I don't think my friends or family really feel that I have it to any extent, or that it has impacted me that much. I mean I don't really know what to tell them to do either (laughs). I feel like it is such a life-defining thing. It is me in a way. Now I feel like I don't even totally understand it.'*

### ***Service provision***

The narratives of all but one respondent implied the usefulness of specialist support post-diagnosis. They valued the opportunity to discuss their condition with an impartial specialist, who could provide them with the safe environment to

explore the implications of having AS. Respondents felt that getting the AS diagnosis was monumental, life-changing and life-defining, and as such it needed to be processed carefully, with help to integrate it in their lives to ensure its benefits.

Crystal described the emotions that the diagnosis of AS brought up in her along with the realisation of the persistent nature of this condition that in her view needed to be shared.

*'Someone to work through all those things with you, that now you know it's you and you're not really going to change, how do you go forward with that? Especially knowing that that's how you are and how your life is going to be. How do you make that a positive now that we know that there are these things that you can't do? How are we going to make life work for you? Because it is so life changing that you need to be prepared and have people on side to share this with. You need to have proper support, but that might not be from your friends and family if they aren't quite as interested as you are'. (Crystal)*

For Mike, apart from the support focused on coming to terms with AS, it was important to receive assistance with employment. He said:

*'I know Google and a lot of other big companies now specially employ autistic people, so I don't know if it would be possible to link up with someone like that in some way. Then you could go, after a diagnosis, "oh, there is actually a potential to get very good employment". If I had some means of then being directly connected to some real work that is sustainable, that would be a big help. Then you don't have to worry so much financially. I'm not saying you're guaranteed to get a job, but at least you can miss all the gaps that you have to think about filling, and go straight to think about moving forward.'*

Nathan did not seek any support noting that post-diagnostic support is not warranted in all cases.

*'It's not something you just pick up, it was there the whole time. If you believe that you were alright beforehand, then you are still pretty-much alright now, it's not something where you feel perfectly healthy one day and then you've got a tumour or a particular condition and it can deteriorate'. (Nathan)*

## **4. Discussion**

### **4.1. Findings**

This study aimed to illuminate the lived experience of those receiving a diagnosis of ASD in adulthood. IPA was applied to collate and analyse rich data obtained in semi-structured interviews.

Upon the thorough analysis of transcripts, fifteen themes were selected based upon their frequency and relevance to the research question. These were then clustered, generating four superordinate themes: the struggles of being a misfit, revelation, realisation (making meaning of the self and AS), and the value and importance of support. As such, the results of this study largely support the findings of previous studies by Bargiela *et al.* (2016), Powell & Acker (2016), Punshon *et al.* (2009) and Cousins (2001). Thus, majority of respondents reported concrete and abstract struggles prior to their diagnosis; being bullied in schools, difficulties retaining their jobs; feeling they did not fit across a range of social contexts. They often pretended to be normal, which they found exhausting. Interestingly, the camouflaging, described by Bargiela *et al.* (2016) as one of the prominent features of female ASD phenotype, appeared to be also present amongst male respondents of this study. Notwithstanding their efforts to be like others, they continued to be easily identified as 'different' by their peers rather than professionals, akin to Bargiela's *et al.* (2016). The discovery that their behaviours and experiences attracted a label of AS and its subsequent affirmation elicited a sense of relief that was also captured by Punshon's *et al.* (2009) and Cousins (2001). Without having clear understanding of reasons for their difference or difficulties, respondents ascribed them to their own flaws and failings, which may have amplified their sense of shame. The exoneration of shame noted here is consistent with the 'not guilty verdict' found in the study by

Punshon's *et al.* (2009) and similar to the 'liberating revelation' described by Kong (2012) in the study on the reactions to a diagnosis of dyslexia. The respondents were avowedly aware of their difficulties and did not respond with shock and disbelief as other young adults attracting the diagnosis (Huws & Jones, 2008). Unlike the previous studies, the current research also captured the respondents' need to receive a formal diagnosis of AS. Although the majority were able to fully identify themselves with the AS profile, they were fearful of being wrong and needed to be certain. Therefore, it is possible that the experience of receiving a diagnosis of AS in individuals, who did not actively seek it or had difficulties identifying themselves with the AS profile might be very different.

The AS diagnosis offered 'the explanation' of respondents' longstanding difficulties and differences, and appeared to ameliorate a sense of shame and personal culpability, akin to Bargiela *et al.* (2016), Powell & Acker (2016), Punshon, *et al.* (2009) and Cousins (2001). It enabled the participants to reframe their past struggles, offered relief, it invoked a sense of loss of, and regret for, significant phases of their lives, experienced without support. Interestingly, this research captured not only the initial relief but also the respondents' hope for change and better life as well as the subtle dynamics in both the respondents' cognitive and emotional representations of their diagnosis. Unlike previous studies, the current research implies that a diagnosis of AS itself was subject to re-appraisal leading to a series of emotional shifts. The initial relief was quickly replaced by confusion, anger, sadness and resentment. The respondents were more or less hopeful. The positives and negatives seemed to be inextricably linked with their experience of obtaining the diagnosis that brought both loss and gains. This dissonance might have been particularly challenging for individuals with AS, characterized by their polarised thinking and cognitive and behavioural rigidity.

Nonetheless, the findings of this study suggest that the notion of AS seemed fluid and coloured by the post-diagnostic life circumstance. It was neither abstract nor monolithic; less of a simple passive output and more of a dynamic notion influenced by the situational context. The respondents viewed their AS as a condition one day and a disorder the next day. It was enabling when they were

required to work on projects in a systematic and focused manner and disabling when they could not manage social situations.

The respondents' perception of their diagnosis was further influenced by others' reactions to disclosure, beliefs of family, friends and society as well as the availability of support, akin to Bargiela *et al.* (2016) and Punshon *et al.* (2009). As such, the meaning-making process did not occur in a vacuum or isolation. The participants commented on the support provided to them by family, friends or professionals where the former was not available. This seems to be consistent with models of adaptation to diagnosis of chronic illness that emphasise the role of social support in psychological adjustment (Holland & Holahan, 2003, Helgeson *et al.* 2004). Further to that, the value of specialist post-diagnostic support was also noted here regardless of whether or not it had been delivered, similarly to the studies by Powell & Acker (2016) and Cousin (2001).

For some, the self-enhancing quality of AS diagnosis might have been diminished because of the lack of support and lack of validation of their diagnosis by friends and family. In others, the journey through pre-diagnosis suffering, post-diagnostic recognition of vulnerability and loss along with the existential re-evaluation and reappraisal served as catalyst for change and rapid growth. The change, however, does not seem to fit with a simple model that imposes one-dimensional trajectory. Unlike the models of bereavement that posits an orderly progression through distinct stages of adjustment (Kubler-Ross, 2007), the respondents' experiences did not follow a sequence of categorical phases.

The results of this study imply that a diagnosis of AS is not a single event but a process comprised of a range of psychological, emotional and social shifts with respondents forever changed by it. As such, it may resemble the concept of posttraumatic growth (Tedeschi & Calhoun, 2004). The respondents' post-diagnostic efforts to construe the self and to make sense of diagnosis within the context of their life were reported explicitly as transformative, akin to Bargiela *et al.* (2016), Punshon's *et al.* (2009), Cousins (2001). Although AS diagnosis was not reported as threatening or traumatic, life prior to their diagnosis was challenging in process and events cited. Disclosures of bullying, failures at work

and in relationships, inability to meet the perceived societal norms or simply inability to be like others seemed deeply distressing. These experiences however gained a new meaning within the realm of AS diagnosis; the respondents no longer felt the need to mask or conceal their difficulties or to pretend to be normal as these were labelled and validated. Their negative experiences were re-appraised allowing self-acceptance and growth. As Carol Rogers pointed out – the self-acceptance (focus on who one is rather than who one is not) seemed to enable change and the growth (Rogers, 1961), and underpinned a formation of new and fuller identity (Garnefski & Kraaj, 2010; Zebrack, 2000), akin to Bargiela *et al.* (2016), Punshon *et al.* (2009) and Cousins (2001).

Unlike previous studies, the current research seems to capture the respondents' active engagement in the meaning making involving both assimilation (changing the meaning of the event) and accommodation (changing beliefs to accommodate the meaning of the event), which may ultimately lead to better adaptation (Park, 2010; Park *et al.* 2008). The latter was manifested by their ability to utilise their knowledge of AS in day to day life. As in the Taylor's (1983) model of the positive adjustment (adaptation), the majority of respondents engaged in a cognitive search for meaning and taking control over the condition (AS symptom management). In contrast to that model and in line with the findings by Bargiela *et al.* (2016), the respondents found comfort in finding equals rather than the downward comparisons (Baumeister, Leary, 1995). Their diagnosis ultimately offered legitimisation and validation of self and social identity (Turner, *et al.* 1987) as well as a sense of belonging and fitting in. The findings do not suggest the burden of stigmatization and vindication that is present in the context of mental health and HIV diagnoses (Julet & Nettleton, 2011, Horn, Johnstone & Brooke, 2007). Although the respondents feared stigma and discrimination, their actual experience of disclosure was largely positive.

Interestingly, in their quest for meaning, none of the respondents gave attention to a question that seems to be prevalent when one is faced with adversity, that is, 'why did it happen to me' (Stanton & Revenson, 2007). Neither did they make any reference to spirituality that is considered an important factor in meaning-making (Park, 2013), which is consistent with the findings from previous studies.

## **4.2. Limitations**

The current study is not without limitations. First, whilst IPA allowed insight into a particular experience of a relatively homogenous sample in a particular context, it limited the generalizability of findings. The conclusions drawn are therefore specific to the respondents. Second, the methodology was based upon retrospective recall that can be biased and restricted by individuals' abilities. Although it is postulated that accuracy of recall improves if it refers to meaningful and significant events (Balxter & Paterson, 1982). Third, the consideration should be given to core difficulties of individuals with AS that relate to their communication, abilities to articulate emotional states and reflexivity. The research sample was selected purposefully and included adults that were highly functioning. This imposes further questions regarding generalisability of findings. The sample clearly favoured individuals, who actively sought a diagnosis of AS, who may have invested emotionally in obtaining the diagnosis, leading to the overemphasis of positive initial responses. Also, the respondents have been diagnosed no longer than two years from the date of the interview and their reflections may change in time.

Lastly, this research was conducted from a critical realist perspective by the researcher who was familiar with the service and respondents, who approached the subjects with some presumptions. However, the researcher identified her assumptions and remained reflective throughout the research process (Robson, 2004; Tong et al., 2007, Brocki & Wearden, 2006; Appendix G).

## **4.3. Clinical Implications and Future Research**

The difficulties experienced by respondents prior to their diagnosis emphasise the need for professionals to be attentive to shame that adults with undiagnosed AS carry, and this, should be addressed in post-diagnostic support. The importance and value of the latter has been clearly documented. It transpired that individuals with AS despite their insights and motivation to be diagnosed with AS should be offered emotional and practical support particularly if there is no evidence of family support. Furthermore, psychoeducational sessions should be offered to

relatives to increase their understanding of AS. A particular consideration should be given to the development of local support groups by voluntary and/or charitable organisations to allow individuals with AS to share their experience with like-minded people. It is equally important that the resources are allocated to specialist adult services so that the ASD assessments are offered to individuals in later stages of life.

A number of areas worthy of further exploration have been also identified. First, a longer-term follow-up or longitudinal study might be useful to capture the trajectory of adjustment to the AS diagnosis. In-depth qualitative research could also include partners to investigate possible changes in the dynamics of their relationship. Considering the role of social identity and sense of belonging/fitting in, it might be useful to explore the differences in receiving a diagnosis of AS and ASD, based upon DSM-V. It also seems important to investigate the experience of receiving a diagnosis of ASD across the full range of severity of ASD as well as those, who does not seek it actively.

#### **4.4. Conclusion**

In summary, the current research highlights the complexity of the experience of receiving a diagnosis of AS in adulthood that is likely to follow a nonlinear trajectory, characterised by the oscillation between different emotional states. Despite being diagnosed late in life with a condition of persistent nature, the research findings indicated that the diagnosis of AS enabled the respondents to grow. Although it is not postulated that receiving a diagnosis is the only context in which individuals can grow and develop, its role should be acknowledged.



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## **Appendices**

### **Appendix F. Researcher's Epistemological Position**

The current research was conducted from a critical realist epistemological stance. As such, it integrates the realist ontology with relativist epistemology (Issac, 1990). It postulates that individuals exist in a reality that is independent of our consciousness and thoughts (Eatough & Smith, 2008; Houston, 2001), although the meaning made of that reality is socially constructed (Oliver, 2012).

The critical realism stance reflects the researcher's beliefs that there is a reality that cannot be seen as objectively knowable; that we make sense of that reality within the context of our social experiences. Critical realism points towards a subjectivity in the process of production of knowledge. The researcher therefore is aware that the knowledge produced through interpretation reflects some aspects of an underlying truth or reality, and so, the offered understanding is partial, as it is not impossible fully to access that real experience (Willig, 2008). In other words, the researcher posits that mental states and attributes, such as meanings and intentions are part of the real world despite being not directly observable.

It appears that critical realist is consistent with IPA methodology and its phenomenological epistemology. Thus, critical realism posits that 'the relation between the real world and the concepts we form of it is the focus of the research process (Denermakr, et al. 2001). Thus, the researcher 'investigates and identifies 'relationships and non-relationships, respectively, between what we experience, what actually happens, and the underlying mechanism that produce the events in the world (Bhaskar, 1978). IPA acknowledges the subjectivity of meaning making in a double hermeneutic cycle, in which the participants make meaning of their experience that the researcher attempts to decode to make sense of the participants meaning making (Smith & Osborn, 2008). And so, the researcher applying IPA from the critical realist perspective admits an inherent subjectivity in the process of generating the knowledge.

From this epistemological stance, the researcher acknowledges the influence of her own reality, that is, her experience of the research process and her interpretations of the respondents' descriptions of their experience (Smith et al., 2009). It is therefore emphasized that the produced account is not and cannot be considered an absolute truth of reality.

It is important to add that the researcher is a Clinical Psychologist specialising in ASD, who worked in the service from where the respondents were recruited. And so, the researcher had a knowledge of the respondents, their history and issues that adults with ASD might experience in response to their diagnosis as well as of the challenges faced by specialist adult ASD services in the UK. The latter was a primary motivation for this research.

## Appendix G. Reflexivity statement

The researcher recognised that her familiarity with the respondents and issues that relate service provision, and her own experience of diagnostic assessments may influence the research process, particularly collection, analysis and interpretation of data. The researcher reflected upon these experiences and identified the following pre-existing assumptions:

- Individuals with undiagnosed ASD struggle considerably without understanding of reasons of their difficulties.
- The confirmation of AS diagnosis is significant and leads to positive outcomes.
- Adults with ASD will struggle to make sense of their diagnosis and its impact on their day to day functioning.
- Adults with ASD will require post-diagnostic support to come to terms with their diagnosis.



## Appendix H. Interview Schedule.

1. When did you first realise that you might be somehow different to your peers?  
*[When did you first realise that you might have some difficulties that others do not]*
2. Did you suspect that you might have ASC before you were formally diagnosed? How did you feel when you thought you might have ASC?
3. How did you feel at the start of the assessment process?
4. Tell me exactly what happened when you were given your diagnosis? How did you respond? What were you feeling/thinking at that very moment? Was there anything you worried about? Did you understand why you were diagnosed with ASC?
5. How did you feel about having a diagnosis of AS later on? *[What did it mean to you? What is it like to you to have ASC? What was the worst/the best thing about being diagnosed? What bothers you most?]*
6. Did you disclose your diagnosis to others? Whom?
7. How being diagnosed with ASC has impacted your life? *[How being diagnosed with ASC has impacted on you as a person? How has your life changed since being diagnosed?*
  - a. *Medically*
  - b. *Emotions/feelings*
  - c. *At home*
  - d. *School/work*
8. What do you think of your diagnosis of ASC now? What does it mean to you now?
9. What would you say to someone who has just received a diagnosis of AS?
10. Is there anything else that is important for me to know about your experience of being diagnosed with AS?

## Appendix I. Approval of the Research Project

Audit Proposal Form (APF) / Research Proposal

Please complete **ALL SECTIONS** of the form and forward to:

[Redacted contact information]

|                          |                   |
|--------------------------|-------------------|
| <i>(Office use only)</i> |                   |
| <b>Date Received:</b>    | Audit Ref. Number |

|  |  |
|--|--|
| <b>1(a) Audit lead details</b>   |  |
| <b>Name:</b> Joanna Beckett  | <b>Job title:</b> Clinical Psychologist    |
| Work Address: [Redacted]   |  |
| <b>Telephone:</b> [Redacted]   | <b>E-mail:</b> [Redacted]                  |
| <b>1(b) Audit Title:</b><br>The Lived Experience of a Diagnosis of Asperger Syndrome in adulthood. |  |
| <b>Audit start date:</b><br>01 November 2016   | <b>Audit end date:</b><br>20 December 2017 |

|   |  |   |
|---|--|---|
| <b>1(c) Please tick ✓ one box: Is this Audit a:</b>   |  |   |
| <b>Clinical Audit (eg, Measures a standard)</b><br>✓ <b>Research Project</b>  | <b>A Service Evaluation (eg, Patient Survey)</b>                   |   |
| <b>1(d) Which Care Quality Commission Outcome, NHSLA Standard or National Best Practice Standard / NICE guidance does this audit relate to: Please tick ✓ relevant boxes or describe:</b> |  |   |
| Involvement & Information<br><input type="checkbox"/>   | Personalised care, treatment & support<br><input type="checkbox"/> | Safeguarding & Safety<br><input type="checkbox"/>     |
| Suitability of Staffing<br><input type="checkbox"/>   | Quality & Management<br><input type="checkbox"/>                   | Suitability of Management<br><input type="checkbox"/> |

**2 (a) Overall Audit aims, e.g, purpose of the audit?**

To explore experiences a late diagnosis of AS in adulthood  
 To offer a rich, descriptive and interpretative accounts paying attention to the meaning ascribed to the AS diagnosis  
 To inform the content and format of post-diagnostic adjustment sessions

**2(b) Specific objectives. What are the audit guidelines or standards being measured?**

Research questions

How do adults experience their late diagnosis of AS?  
 How do adults ascribe the meaning to their late diagnosis of AS?  
 How do they make sense out of this diagnosis?

**2 (c) In which ways do you think the audit will improve patient care / outcomes?**

As a part of the assessment process, our clinic provides post-diagnostic adjustment sessions to clients and family members. There is currently no framework, within which this is offered. Practitioners share their knowledge of autism (psycho-education) with clients and so, the post-diagnostic sessions are largely based on psycho-education. However, there is no indication of what actually facilitates their adjustment process. Thus, the research findings will be used to inform the content and format of the post-diagnostic adjustment sessions. They will also offer a valuable insight into how the assessment processes is experienced by clients, which will shape practitioners' approach to the diagnostic assessment.

**3 (a) Type of Audit Please Tick ✓ where appropriate – more than one might apply**

|                       |                          |                     |                          |               |                               |
|-----------------------|--------------------------|---------------------|--------------------------|---------------|-------------------------------|
| (A) National          | <input type="checkbox"/> | Mandatory e.g. PEAT | <input type="checkbox"/> | Non-mandatory | X<br><input type="checkbox"/> |
| (B) Organisation-wide | <input type="checkbox"/> | Directorate based   | <input type="checkbox"/> | Team based    | X<br><input type="checkbox"/> |
| (C) Multidisciplinary | <input type="checkbox"/> | Uni-disciplinary    | <input type="checkbox"/> | Borough Led   | <input type="checkbox"/>      |
| (D) Multi-agency      | <input type="checkbox"/> |                     |                          |               |                               |

Other (please state):

This research project forms a part of the portfolio for Professional Doctorate in Clinical Psychology (DPsych Top up at Leicester University).

**3 (b) Does your audit criteria apply to any of the following? If so Please Tick ✓ where appropriate**

|                                  |                          |                                |                          |                                   |                          |
|----------------------------------|--------------------------|--------------------------------|--------------------------|-----------------------------------|--------------------------|
| NHS Litigation Authority (NHSLA) | <input type="checkbox"/> | Care Quality Commission CQC    | <input type="checkbox"/> | Risk Register                     | <input type="checkbox"/> |
| Organisational Policy            | <input type="checkbox"/> | ██████████ Strategic Objective | <input type="checkbox"/> | Patient Survey                    | <input type="checkbox"/> |
| NICE guidance                    | <input type="checkbox"/> | Your Healthcare Business Plan  | <input type="checkbox"/> | DH Policy Implementation Guidance | <input type="checkbox"/> |
| National audit                   | <input type="checkbox"/> | Improving working lives        | <input type="checkbox"/> | Essence of Care                   | <input type="checkbox"/> |

Other (please state, e.g. Issue of local concern):

**4(a) Who will be on the audit steering group and what consideration has been given to the involvement of patients, carers or the public?**

This research will involve clients with ASC.

**For more information on Information Governance, please contact: Teresa Candfield or Marjan Daneshpour**

**5) Data Collection (please consider, and where possible answer all of the following questions)**

|  |  |
|--|--|
| <b>5(a) Where from?</b> Audit data can be collected from many sources including: medical records/RiO, nursing records, patients, clinicians, and other staff.  | Individual and semi-structured interviews with clients with AS               |
| <b>5(b) How?</b> The data source will obviously influence the method used to collect data. E.g. If data is to be collected from patients the most appropriate method might be a survey or interview. If data is to be collected from medical records, it will be necessary to design a data collection proforma. Questionnaires, one-to-one interview, focus groups. | Semi-structured interview; a set of 10 – 15 questions will guide interviews. |

|  |   |
|--|---|
| <p><b>5 (c) How much?</b> As a guide, a sample should include a minimum of 30 cases and perhaps as many as 100. If the initial sample proves to be too small to provide data necessary, it can be added later.</p>   | <p>Between 6 – 8 clients with AS.</p>         |
| <p><b>5 (d) Who?</b> Who will be responsible for collecting the data? Ensure the person identified understands their role.</p>   | <p>Joanna Beckett (Clinical Psychologist)</p> |
| <p><b>5(e) Timescale?</b> Over what period is the data to be collected?</p>  | <p>April 2016 – November 2016</p>             |
| <p><b>5 (f) Pilot Audit? Y/N</b> In most cases it will be advisable to carry out a pilot to check quality of questionnaire, length of interview, etc. In light of the pilot audit findings, modifications to any of the above may need to be made. Smaller sample is appropriate for pilots.</p>   | <p>Y</p>                                      |
| <p><b>6(a) Who may be affected by the outcomes of this Audit?</b><br/> Ethical considerations are integral to designing this research given that the study will attempt to recruit potentially vulnerable participants.</p> <p>The outcomes of this research should not affect anyone. Participants will have a right to withdraw at any stage.</p>  |   |
| <p><b>6(b) With whom and where will the final report be shared? i.e Local service area governance committee, Integrated Governance Committee,?</b><br/> Internally: the final report will be saved on the shared drive so that practitioners will be able to access it.<br/> Externally: the final report is a part of the DPsych portfolio that will be shared with Leicester University.<br/> The identity of clients/participants will not be shared. Clients' names will be removed from the report so that they will remain unidentifiable.</p> |   |
| <p><b>6c) Who will take responsibility for disseminating the results of the audit and following through recommendations? And how and when will the recommendations be evaluated, monitored and reviewed? Names and role.</b><br/> Joanna Beckett to disseminate the results of this research in Psychology Meeting. The recommendations will be discussed with my clinical supervisor, [REDACTED]. These will be implemented, evaluated, monitored and reviewed by Joanna Beckett.</p>   |   |
| <p><b>All completed audits must be followed up with a completed recommendations monitoring form, available on the [REDACTED] intranet site</b><br/> <a href="#">LINK TO GO HERE</a></p>  |   |

7 Ethical Approval – if required please contact Maggie Elliott on:  
[Maggie.Elliott@stgeorges.nhs.uk](mailto:Maggie.Elliott@stgeorges.nhs.uk)

|   |   |
|---|---|
| <p><b>Ethics approval given by:</b><br/>Dr Karen Long</p> <p><u>Karen LP.</u></p> <p><b>Date ethically approved:</b><br/><u>13 September 2016</u></p> | <p><input type="checkbox"/></p> <p><input type="checkbox"/> Name of possible committees that would give ethical to go here.</p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> |
|---|---|

| <b>8 (a) For which of the following do you consider you may need assistance from the Quality, Assurance &amp; Governance Manager / Quality &amp; Audit Lead? – put your role first!!</b> |                          |
|--|--------------------------|
| Literature searches  | <input type="checkbox"/> |
| Developing standards   | <input type="checkbox"/> |
| Initial meetings   | <input type="checkbox"/> |
| Planning meetings  | <input type="checkbox"/> |
| Questionnaire design   | <input type="checkbox"/> |
| Pilot  | <input type="checkbox"/> |
| Amendments to questionnaire  | <input type="checkbox"/> |
| Data collection  | <input type="checkbox"/> |
| Data analysis  | <input type="checkbox"/> |
| Report writing   | <input type="checkbox"/> |
| Presentation writing   | <input type="checkbox"/> |
| Presentation   | <input type="checkbox"/> |
| Binding of report and distribution   | <input type="checkbox"/> |
| Make recommendations for improvement   | <input type="checkbox"/> |
| Other assistance (please state what you require)   | <input type="checkbox"/> |

## Appendix J. Notes from University Ethics Review

|   |                        |
|---|------------------------|
| Created By:   | Todor Gerdjikov (tv3)  |
| Role Type:  | Secondary Reviewer     |
| Date Added:   | 06/04/2017 10:07:55    |
| <p>Regarding this sentence "They will be given a contact details to [REDACTED], Clinical Psychologist at [REDACTED] should they wish to discuss their feelings." has [REDACTED] agreed to set time aside to meet people who may contact her. Also I wasn't sure why the main applicant is not able to offer to discuss concerns either in a follow-up meeting or set time aside immediately after the interview, as they appear to be a qualified clinical psychologist themselves.</p> |                        |
| Created By:   | Joanna Beckett (jb624) |
| Role Type:  | Applicant              |
| Date Added:   | 11/04/2017 15:49:51    |
| <p>[REDACTED] agreed to meet the participants individually if they wish to discuss their feelings after the interview. I will also set time aside immediately after the interview to do so. However, I wanted to ensure that the participants have options of addressing their concerns with either the researcher or an independent qualified psychologist.</p>  |                        |
| Created By:   | Joanna Beckett (jb624) |
| Role Type:  | Applicant              |
| Date Added:   | 11/04/2017 18:50:26    |
| <p>I have attached the amended version of PIS Participant Information Sheet 2. Please ignore previous version. I do apologise but I was not able to replace this file.</p>  |                        |
| Created By:   | Jose Prados (jpg19)    |
| Role Type:  | Reviewer               |
| Date Added:   | 25/04/2017 15:59:14    |
| <p>The application has been revised addressing the comments of the Ethics Officers. The ethical issues have been adequately addressed.\n</p>  |                        |

## Appendix K. Chronology of Research Process

|                                 |  |
|---------------------------------|--|
| <b>December 2014</b>            | Initial discussions with Joint Managers of AS Service  |
| <b>January 2015</b>             | Finding research supervisor  |
| <b>April 2016</b>               | Scoping of literature and development of research proposal   |
| <b>June 2016</b>                | Submission of initial research proposal to University of Leicester (UoL)   |
| <b>June – September 2016</b>    | Refinement of research proposal  |
| <b>September 2016</b>           | Submission of research protocol to the Clinical Governance Committee<br>Approval of research protocol by Clinical Governance Committee |
| <b>March 2017</b>               | UoL peer review of research proposal   |
| <b>April 2017</b>               | Approval of research proposal by UoL   |
| <b>May – August 2017</b>        | Recruitment and interviewing of participants<br>Interview transcription  |
| <b>August – November 2017</b>   | IPA analysis and preparation of research report  |
| <b>November - December 2017</b> | Preparation of critical appraisal  |
| <b>December 2017</b>            | Submission of thesis to UoL  |
| <b>January – February 2018</b>  | Dissemination of research findings to participants<br>Preparation of research summary for AS Service<br>Publication of findings        |



## Appendix L. Participants Information Sheet



### Study Information Sheet

Title of research study: The lived experience of a diagnosis of an Autism Spectrum Condition in adults.

I would like to invite you to take part in my study. Before you decide I would like you to read this Information Sheet so that you understand why the research is being done and what it would involve for you. Joining the study is entirely up to you.

#### **Reasons I am doing this research**

I would like to learn more about how adults respond to their diagnosis of an Autism Spectrum Condition and how they make sense out of it. I hope that this will help me to develop a better post-diagnostic support for our clients.

#### **How I will do the research**

I would like to interview 6 people with ASC. I will ask questions about how they felt about being referred for a diagnostic assessment, what they thought of their diagnosis and how they felt when they received a diagnosis of ASC.

#### **Taking part in in the study**

You do not need to take part in this study. To help you decide whether or not to take part, you can talk it over with your friends or family. I am also happy to answer any questions you may have about this study.

- ▶ Even if you agree to take part, you do not need to answer all the questions in the interview. You can withdraw from the study at any point.
- ▶ Your name and other personal details about you will be kept anonymous.

#### **What you will do if you take part**

- ▶ If you decide you would like to take part in this study, the next step is to complete the enclosed Consent Form. You can send the Consent Form back to us using the self-addressed envelop or bring it to Sheridan House and leave in the drop box in the reception area.

- ▶ If you do not want to take part in this study, you do not have to do anything. It will not affect your future care.
- ▶ Once I receive your Consent Form, I will invite you to meet me at Sheridan House. I will explain the study to you and you will be able to ask me questions about this study which I will answer. If you are still happy to take part, we will start the interview.
- ▶ The interview will last no longer than 1.5 hours. We can take breaks in between if you wish.
- ▶ I will ask you questions about how you felt when you were given a diagnosis of ASC.
- ▶ I will be recording your answers on a digital recorder and making some notes.
- ▶ You can come to your interview with a friend or family member.

### **The benefits and risks of taking part**

- ▶ There are no direct benefits to you if you take part in this study.
- ▶ Taking part will contribute to helping us understand how to best work and support adults with ASC.
- ▶ The interview is not meant to be intrusive. However you may find some of the questions quite personal.
- ▶ Many people find it helpful to talk about their experiences of being diagnosed with ASC, but other people may find it upsetting.
- ▶ Following the interview, I will ask you whether you have any concerns that you want to address. For instance, you might want to discuss the feelings the interview brings up in you. You will be able to discuss it with me immediately after the interview. I will also give you my details and contact details to my colleague, Dr Jo Coombs, Clinical Psychologist, who you can also talk to if you find the interview upsetting.

### **A note about confidentiality**

- ▶ All information about you will be kept strictly confidential in line with the Data Protection Plan 1998.
- ▶ Your name and all personal details about you will be kept anonymous.
- ▶ When the recording is typed up these personal details will be taken out or changed.
- ▶ The audio recording will be deleted once the research has been submitted to the University of Leicester.
- ▶ When I write the research I will use quotations of what people say. The quotations will be carefully picked so that they do not contain any information about you.
- ▶ I will talk to a psychologist at the University of Leicester about the research to help me conduct the research properly. I will not use your name, or mention information, which identifies you.
- ▶ I might break confidentiality, if I am seriously concerned about your safety or the safety of other people as I have a professional duty to

ensure that I can keep you or other people safe. If this happens, I would have to contact your GP or another professional that works with you. I will discuss it with you before contacting them.

### **When someone might be told what you have said in the interview**

- ▶ Some people might feel upset in the interview.
- ▶ Before we do the interview we will agree on a clinical professional who we can contact if you get upset.
- ▶ This could be someone like your GP, social work or another professional who supports you.
- ▶ We will tell this person that you are going to do the research.
- ▶ If you get upset in the interview and want more support, we can contact this person.
- ▶ I will be also able to meet you following the interview to discuss your concerns. Alternatively, I can ask one of my colleagues to see you.

### **What will happen when the research is finished**

- ▶ I will write a short summary of the research.
- ▶ I will send it to everyone who took part in the research.
- ▶ I will write a longer report of the research to submit to the University of Leicester.
- ▶ This will be kept in the University of Leicester library.
- ▶ I can send you a copy of the longer report if you would like one.
- ▶ I will also write a report that I will submit for publication in an academic journal.
- ▶ Members of the public do not normally see these journals.
- ▶ If the research is published I can send you a copy of the article if you would like one.

### **Who has approved this research?**

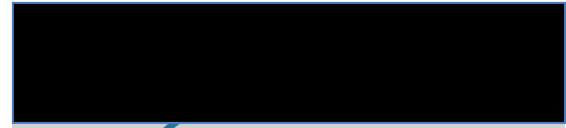
- ▶ The University of Leicester ethics Committee.

### **If there is a problem**

- ▶ If you have any concerns about any aspect of the research, you can contact my research supervisor, Dr Noelle Robertson.

Dr Noelle Robertson  
Senior Lecturer  
University of Leicester  
104 Regent Road  
Leicester  
e-mai: [nr6@le.ac.uk](mailto:nr6@le.ac.uk)

Thank you for taking time to read this Information Sheet.



**The lived experience of a diagnosis of Autism Spectrum  
Condition in adults.**

**Consent Form**

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Please consider and respond to the following points before signing this consent form. Your signature confirms that you are happy to participate in the study. You will receive a copy of this form.

***For each statement, please put your initials in the box to indicate you agree with it:***

- I have read and understood the Study Information Sheet and understand what taking part in this study involves.
- I understand that my participation is entirely voluntary, and that I am free to withdraw from the research at any time without giving a reason. If I withdraw from the study, I understand that any data collected before I withdraw will still be used.
- I understand that Joanna Beckett, Clinical Psychologist, who conducts this research will access information about how I was referred for an ASC assessment.
- I understand that the results from this research will be written up and submitted to the University of Leicester. It also might be published in an academic journal and read by professionals.
- I understand that all the information collected will be treated as confidential. This means that my name, or any other information that could identify me, will not be included in anything written or presented about this research.
- I understand that the information I provide is subject to the Data Protection Act.

***Please turn over***

*Finally, please respond to the following clause which is included in all NHS research consent forms:*

I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust where it is relevant to my taking part in this research.

**I confirm I would like to take part in this study.**

**Signature:** \_\_\_\_\_ **Date:**

\_\_\_\_\_

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

**Thank you for taking part in this study.**

## Appendix N. Frequency of Super- and Subordinate Themes

|   | Monica | Lukas | Crystal | Zara | Mike | Samantha | Nathan |
|---|--------|-------|---------|------|------|----------|--------|
| <b>The struggles of being a misfit</b>                | 0      | 0     | 0       | 0    | 0    | 0        |        |
| Sense of being different                              | 0      | 0     | 0       | 0    | 0    | 0        |        |
| Pretending to be normal                               | 0      | 0     | 0       | 0    | 0    | 0        |        |
| Masking difficulties                                  | 0      | 0     | 0       | 0    | 0    | 0        |        |
| Struggles and suffering                               | 0      | 0     | 0       | 0    | 0    | 0        |        |
| <b>Revelation</b>                                     | 0      | 0     | 0       | 0    | 0    | 0        |        |
| Self-discovery and need of certainty                  | 0      | 0     | 0       | 0    | 0    | 0        |        |
| Explanation   | 0      | 0     | 0       | 0    | 0    | 0        |        |
| Relief  | 0      | 0     | 0       | 0    | 0    | 0        |        |
| Hope for change                                       | 0      | 0     | 0       | 0    | 0    | 0        |        |
| <b>Realisation: making meaning of the self and AS</b> | 0      | 0     | 0       | 0    | 0    | 0        |        |
| Mixed feelings and confusion                          | 0      | 0     | 0       | 0    | 0    | 0        | 0      |
| Self-understanding & self acceptance                  | 0      | 0     | 0       | 0    | 0    | 0        | 0      |
| Late diagnosis  | 0      | 0     | 0       | 0    | 0    | 0        |        |
| Identity  | 0      | 0     | 0       | 0    | 0    | 0        | 0      |
| AS management   | 0      | 0     | 0       | 0    | 0    | 0        | 0      |
| <b>The value and importance of support</b>            | 0      | 0     | 0       | 0    | 0    | 0        | 0      |
| Support from family and friends                       | 0      | 0     | 0       | 0    | 0    | 0        |        |
| Service Provision                                     | 0      | 0     | 0       | 0    | 0    | 0        | 0      |

**PART FOUR: CRITICAL APPRAISAL OF THE  
RESEARCH**

## Critical Appraisal

### 1. Overview

This is an attempt to present my professional and personal reflections on the research process. I will focus on capturing my experiences as I progressed through different stages of the research journey as well as appraising the methodology applied, limitations of the study and the learning gains.

### 2. Project selection

As a Clinical Psychologist, working in an Asperger Syndrome (AS) specialist service, I have been aware of the challenges and gaps in service provision, reinforced by a lack of health services research for adults with ASD (Autism Spectrum Disorder). While the services for children with ASD are relatively well established, the provision of diagnostic assessments and psychological interventions for adults with ASD continues to be underdeveloped and overlooked (Murphy, *et al.* 2016; Lake, *et al.* 2014). In addition, the number of undiagnosed adults remains relatively high despite the advancements in the early detection of autism. (Woodbury-Smith, *et al.* 2010). Therefore it is not uncommon that those individuals to develop secondary mental health conditions that overshadow the underlying neurodevelopmental disorder (Murphy, *et al.* 2016). The majority of clients referred to our service for a specialist diagnostic assessment have already established mental health diagnoses. Understandably, receiving yet another *label* may elicit complex emotions. Considering that there is no cure or treatment for AS, receiving this diagnosis can be very challenging.

The NICE Guidelines recommend that adults receiving a diagnosis of autism spectrum disorder (ASD) are provided with post-diagnostic support to facilitate their adjustment process, increase their understanding of the symptomatology, and ultimately – to enable them to manage their difficulties effectively. There is however no identified high-quality, evidence-based and cost effective models of post-diagnostic care (Murphy, *et al.* 2016).



Since the literature on the ASD diagnosis in adults is scarce as most research on autism focuses on early childhood, I decided to examine the experience of a late diagnosis of AS amongst our clients. I hoped that the research findings would provide me with better insights into the complexity of this phenomenon, which could inform the development of effective post-diagnostic support programmes.

Upon undertaking a literature search on the experiences of receiving various diagnoses, it was evident how little attention has been given to the examination of adults' responses to a diagnosis of neurodevelopmental conditions. I also found myself particularly interested in one of the aspects of the adjustment process, that is, meaning making. At that time I faced a health scare myself and observed my own response to my diagnosis, and the way I was making sense of it. I also felt that I needed to *process* my own experience of receiving a diagnosis before exploring the experiences of my clients.

### **3. Design, Method and Procedures**

When deciding on a methodological approach, I was certain that a qualitative approach would be most aligned with the nature of my enquiry. First, the subject is under-researched. Second, individuals with AS often find questionnaires or rating scales confusing. Third, I felt that participants' familiarity with the service and myself would facilitate their engagement with the research process. The latter, however, was also raising ethical questions. I was mindful of the power imbalance and their potential sense of obligation to take part in the study. It was therefore paramount to ensure that the clients are aware that their decision has no bearing on future service provision and their participation is voluntary. The differentiation between my role as a researcher and a clinician was also clarified to prevent from falling into a 'client – clinician' dynamic.

While deciding on methodology, I determined Interpretative Phenomenological Analysis (IPA) to be the most suitable approach for capturing the lived experience and investigating how individuals are making sense of their personal and social

world, which was at the heart of my project (Smith, 1996; Smith, Jarman & Osborn, 1999, Smith & Osborn, 2008). However, I was conscious that I might not be able to obtain rich accounts given participants' communicative deficits, imposed by their condition. However, IPA allowed me to select my research sample purposefully and involve individuals with AS presenting with a good ability to express their cognition and emotional states. I also contacted Jonathan Smith, who developed IPA to ensure that my sampling process was in line with the IPA principles. In addition to that, I discovered and joined his online IPA Yahoo Group, which I found very informative.

The nature of AS, with its core difficulties, were taken into consideration while planning and conducting the research. I felt that my expertise in the subject as well as familiarity with the participants would enable me to create the environment that is conducive to their openness in sharing their very personal thoughts and emotions. To my surprise the recruitment process was completed fairly quickly and the interview sessions were arranged as soon as I received signed consent forms from the prospective participants. Although the interview schedule had been already developed and discussed in-detail with my colleague, an expert in ASD, I worried that the open-ended questions might be 'puzzling' for adults with AS. Given their weak central coherence, that is, a limited ability to see context, I feared that the questions are not specific enough (Happe, 2013). The very first interview however showed that only a few prompting questions were required and these were subsequently included in the schedule and used when needed.

The difficulty of remaining detached and impartial towards the study matter was on my mind throughout the whole research process. Thus, the respondents were asked to describe the experience of receiving the diagnosis that they received from myself. Subsequently, while I was engaged in listening to their stories, I was also aware of my own memories and recollections of their diagnostic assessments. I found myself shifting my focus from my own *story of how they experienced their diagnosis* to their narratives.

Throughout the interview sessions I was capturing my own thoughts that were brought up by my knowledge of the participants and their lives. I was mindful of not bringing them into the interviews. Nonetheless, I did wonder whether my non-verbal behaviour, prompting and encouraging was leading the respondents to focus on particular aspects of their experience while omitting others. I also wondered whether there were areas of their experience of the AS diagnosis or the diagnostic process itself that they chose not to reveal to please me as their clinician and their researcher. In fact, some respondents felt that they did not provide me with clear answers that would fit with my expectations. I found that it was very important to reassure them and explain that I was interested in their personal experiences, their thoughts and emotions, and so there were no right or wrong answers, and no expectations to fit in with some pre-existing model.

The interviews elicited a range of different emotions in the respondents and myself. My first respondent offered a very rich and dense account of the manner in which she was making sense of her diagnosis. She brought in her personal diary that she presented to me after the interview. Her diary included entries she made immediately after receiving her diagnosis of AS, her reflections, pictorial representations of her understanding of AS along with the world 'AUTASTIC' (a fusion of two words: *autistic* and *fantastic*) in the rainbow colours that she created with her autistic child.

Her openness and capacity to share her very personal experiences were striking. As a clinician knowing her story I found myself wondering how well she was actually coping with her day-to-day life and the limitations imposed by her AS. This made me wonder whether *autistic* was in fact *fantastic*, and whether this was her way of coping (positive reappraisal) with her and her child's condition. None of it could be included in my research though and I feared that the data from the interview would not give the full picture of her experience.

My last interview evoked particularly strong emotions of sadness as well as a sense of hopelessness. The respondent was surprised by her own somehow *raw* and often contradictory emotions. She worried that her answers suggesting a sense

of lost hope were *not* fitting in with my agenda while I, as a clinician, reflected on her mood and wondered whether I had provided her with adequate support.

#### 4. Data Analysis

Although I was keen to immerse myself with the data, I found both the transcription and analysis phases of the research particularly daunting and time consuming at first. I was overwhelmed by the richness of the accounts and wondered whether I might not be able to *see the wood for the trees* and would get 'stuck' in details losing the capacity to build a bigger picture. I did however genuinely enjoy reading the transcripts and noticing emerging themes. In doing so, I was mindful of my preconceptions and expectations, and continued to repeatedly return to the original transcript to ensure that my interpretations were grounded in the participants' accounts rather than my own story. This resulted in extracting a relatively high number of quotes to evidence the accuracy and transparency of my interpretation. I found the discussions between PhD students in Yahoo IPA Group reassuring, as it seemed that the apprehension or the reluctance to generate interpretations was shared. In fact, Smith *et al.* (2009) observed that novice IPA researchers doubt their interpretative skills and fear that their interpretation might be far fetching.

As the analysis progressed, I found myself compelled to organise the themes in a particular order to represent distinct phases or stages of the adjustment process. Bracketing off my preconceptions was rather challenging. It was helpful to discuss the emerging themes with my research supervisor as her observations and questions challenged my ideas, and enabled me to consider other perspectives, and look at data with 'fresh' eyes. Many of my assumptions and presumptions were generated as a result of my familiarity with the participants and issues around service provision. Although these were acknowledged at the onset of the research, I had to remain mindful of my dual role throughout the entire process.

## **5. Dissemination**

Considering the primary aim of this research and my role as a clinician, I am strongly motivated to disseminate applicable findings and continue my commitment to the research. It is my priority to share the research results with the respondents to acknowledge their involvement in the project. The research summary will be disseminated to my colleagues, who currently work with clients with AS and added to the shared hard drive so that other clinicians can access it if needed. I also hope that the summary will be shared with our local commissioners to increase their awareness of the needs of those with AS, plus open a discussion about the potential further development of the AS service. I am motivated to share the research findings through future training sessions and development events that I will be a part of.

## **6. My position as a clinician and researcher**

From the very onset of this research I was aware that I do not hold a neutral position in this process. I was a researcher and a clinician, who recruited participants from the pool of clients I had worked with. I was particularly conscious of the ethical issues around by my dual role, especially as my chosen qualitative approach required a direct contact with my clients.

My dual role had to be acknowledged in various stages of this research process (recruitment, data collection, analysis, interpretation; Hay-Smith, *et al.* 2016). As a clinician I did approach the research subject with certain expectations. My intention was to highlight the significance of a late diagnosis of ASD as well as the need for post-diagnostic support. The latter, I hoped, could be presented to the local commissioners when discussing future development of the AS service. I recognised that I needed to pay attention to my perception of desirable and undesirable outcomes, and to allow the voice of the respondents to surface. I was aware of the uniqueness of my position and the potential to make an essential contribution to behavioural health research (Yanos & Ziedonis, 2006). I was, in fact, a clinician, who was addressing the most prominent issues that I observed in

my every day practice. Further to that, I was able not only to disseminate the outcomes but also ensure their implementation.

Notwithstanding these benefits, I was faced with a number of challenges. First, I was seeing the clients I had worked with in a new context and for a different reason. I was no longer offering interventions but gaining information (Thompson & Russo, 2011). In fact, Colbourne *et al.* (2004) suggested that the nurse – researcher or a practitioner – researcher may fear that their qualitative study may inflict harm on participants, which was on my mind throughout the research process. I experienced an internal clash between acting in the best interest of my clients and the mandate to conduct rigorous stud, similar to the one delineated by Yanos & Ziedonis (2006).

I also worried that the respondents might approach this study with certain expectations or a sense of obligation. I was conscious of the power imbalance and the fact that I might be perceived as a gatekeeper that needs to be pleased. I wondered whether they hoped for our meeting to resemble the therapeutic encounter. Furthermore, I worried that I may unintentionally misuse my interviewing/clinical skills to gain information that the respondents would not share otherwise. It was therefore my priority to ensure that they did not feel obliged to take part in this study, understand my role and can refuse to answer or withdraw their participation. As mentioned by Brinkmann & Kvale (2008), the respondents needed to retain their autonomy in the research process.

It was both reassuring and informative to find similar examples of conflicts and resolutions in the literature (Colbourne & Sque, 2006; Chesney, 2001; Wilde, 1992). For instance, Wild (1992) stated that it is not possible to ‘hide’ the clinical skills and any attempts could appear ‘fake’ to participants. I felt it was imperative to remain authentic and natural, and balance both roles rather than try to conceal it.

Nonetheless, I was unable to switch off my ‘clinician mind’, which was particularly pronounced in the interview sessions. Thus, I wondered about the participants’ mental health, their well-being and thought of interventions that they

could find beneficial. I felt my research role was somewhat restricting and developed a sense of guilt for not being able to act as a clinician.

I was not emotionally detached and I did find myself empathising with respondents. I was pleased to see the positive changes they have made since I saw them last and sad to hear about their struggles. Two of the respondents contacted me a few days after their interviews and asked for a referral for therapy. They explained that their requests were not brought up by the research as they had planned to approach their GPs prior to that. The creator of 'AUTASTIC' was one of them, which made me think again of her ways of coping with autism and life. Her accounts of the experience of receiving the AS diagnosis had a predominantly positive tone. Although she did say that she sees AS as a condition one day, and a disorder another day depending on how well she manages her day to day life. Perhaps, it was not AS that she wanted to address through therapy. I was left with a number of questions and no answers. In both cases, I felt *unfair* when responding to the participants' queries and signposting to other services. However, it was also a reminder of why I have decided to research the subject in the first place, that is, to promote AS service development.

On reflection, I would argue that is imperative to acknowledge and embrace both roles, that of a clinician and that of a researcher to remain honest, transparent and authentic throughout. In contrast to researchers and academics my training in research methodology and statistics were not as expansive (Yanos & Ziedonis, 2006). This may have also contributed to my internal sense of imbalance. It also seems to me that the tension generated by dual roles might be inevitable.

## **7. Research Limitations**

There is a number of limitations concerning this study. First, the results are not representative of all adults with AS and cannot be generalised. As such, the findings are specific to the researched sample that consisted of highly functioning individuals with good insight and ability to communicate. Also, majority of them

sought their diagnosis and so their story might differ to the story of those, who struggled to identify themselves with the AS profile.

Second, due to the time constraints the data was collected at one point in time only. A longitudinal study would perhaps provide better insights into the experience of diagnosis.

Future research exploring this phenomenon could potentially include partners or relatives of those with AS. It would be also important to look at a diagnosis of ASD across the full severity of spectrum and include adults with bigger communicative deficits.

## **8. Personal and Professional Reflections**

Admittedly, the biggest challenge I faced while conducting this research was the embracement of the dual nature of my role. I feel I am more prepared to engage in similar project in future. Since my previous research projects were based upon the application of quantitative approach, I found it extremely rewarding and gratifying to familiarise myself with the IPA framework. I enjoyed the opportunity to connect with the respondents, to enter their worlds and to listen to their narratives.

Outside of the research project itself, it was difficult to find balance between my work, research and other activities that are essentially a part of my self-care routine. My own health complications experienced at the beginning of the research project cause me to doubt whether I would be able to manage clinical and academic demands. As a mature student working outside of the campus I felt a bit isolated but the thought of conducting clinically relevant study was gratifying and helped me to persevere.



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