



CENTRE FOR AUTISM
MIDDLETOWN

Autism and Girls Volume 2



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INTRODUCTION

This is the twentieth Research Bulletin produced by Middletown Centre for Autism and it provides summaries of ten articles spanning from 2011-2015. The articles address the area of autism and girls from a range of perspectives using both qualitative and quantitative research methods.

The Bulletin commences with an interview with Dr Judith Gould BSc, MPhil, PhD, AFBPsS, CPsychol. A Consultant Clinical Psychologist. Dr Gould, is the Lead Consultant at the Lorna Wing Centre for Autism and retired as Director of the Centre in 2015. She is a Chartered Consultant Clinical Psychologist, with over 40 years' experience, specialising in autism spectrum disorders and learning disabilities.

Before being the Director of The Lorna Wing Centre she worked as a member of the scientific staff of the Medical Research Council Social

Psychiatry Unit and was a Senior Lecturer at the Institute of Psychiatry, University of London. She has also worked as a Clinical Psychologist within both health and social services. She has published widely in the field of autism spectrum disorders. Her current interest is the diagnosis of women and girls on the spectrum.

Please note that the views represented in this document do not necessarily reflect the views of Middletown Centre for Autism. Reviewers have, where possible, used the original language of the article, which may differ from UK and Ireland usage and the usage of a range of terminologies for autism.

AN INTERVIEW WITH DR JUDITH GOULD

1. Are we getting better at diagnosing girls?

The first conference in the UK on Women and Girls was in 2008. It was brought to our attention that women and girls were not being diagnosed, often resulting in mental health problems.

Following this we had many more referrals to the Lorna Wing Centre for diagnosis of women and girls. With more research and awareness of the different profiles for men and women we are getting better at diagnosing this condition. However, the current International Diagnostic Criteria still do not give examples of the types of difficulties and activities experienced by girls and women. It is important to take a much wider perspective regarding the social, communication and imagination dimensions in addition to the special interests and rigidity of behaviour. Girls and women are skilled at learning how to act in social settings. Unenlightened diagnosticians perceive someone who appears able, has reciprocal conversation and who uses appropriate affect and gestures as not meeting the criteria set out in the International classification systems. Therefore, a diagnosis can be missed.

2. Is this down to greater information and research?

There are now many more papers published on gender differences in autism which highlight that females with ASD may not exhibit behaviours to the same degree as males. In the past there has been an expectation that autism is more common in males than females. This is now recognised not be the case which is backed up by research evidence. Information sharing in conferences and published papers are beginning to change the thinking about diagnosis in females.

The personal accounts from the women have dramatically changed our thinking. Reading autobiographies, blogs and watching YouTube videos made by women have given us much greater insight into the way their autism is manifested.

3. We are learning so much about autism from women, Rudi Simone, Liane Holliday Willey, Ros Blackburn and of course Temple Grandin. What do you think makes it easier for them to explain and discuss their autism?

For this reason we have learned so much more about the female presentation of autism. What can be more appropriate than first-hand information about what it is like to have autism? As a professional you can speculate and hypothesise about patterns of behaviour but cannot experience real life situations. In my clinical work, talking to females about their lives has given me insight into the world of autism. The books written are so helpful and are recommended reading for newly diagnosed females and their families.

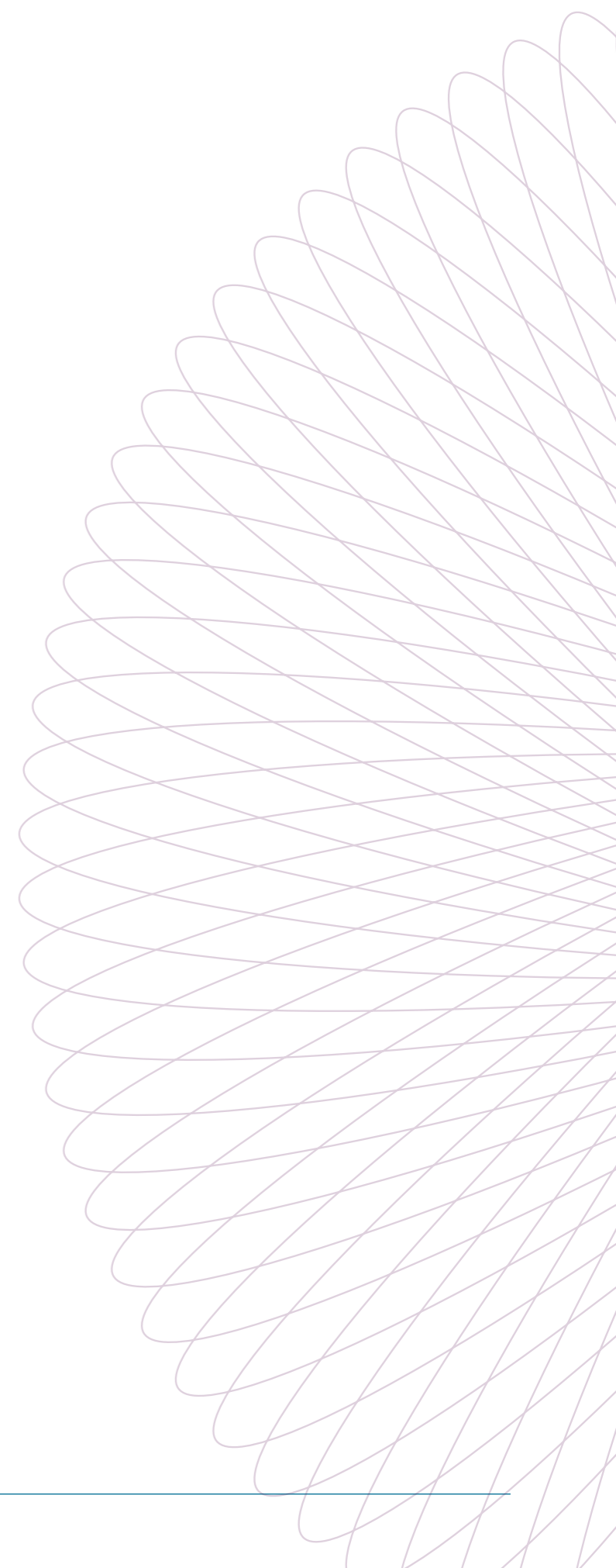
4. What more can we do to identify girls earlier, so that they can avail of early intervention services?

Listen to parents, recognise that the girls are excellent at masking their symptoms. They often behave differently in different settings. Gathering information and taking an appropriate developmental history is essential. It may be only when the child begins formal education that the autism becomes apparent. Being able to recognise the often subtle problems can be difficult for an inexperienced clinician.

In primary school girls on the spectrum may 'get by' and are supported by their peers. Parents may engineer or organise friendships for their daughters. Social difficulties become more obvious in adolescence at secondary school. Taking note of bullying is important. Schools need staff who are trained to recognise the needs of students on the autism spectrum and especially the more subtle presentations in girls. A timely diagnosis can avoid many of the difficulties women and girls on the spectrum experience throughout their lives. A diagnosis gives access to appropriate support and understanding from those who offer early intervention services.

5. Have you noticed a difference in the 'special interest' or as Ros Blackburn says 'rip roaring obsessions' of girls with autism from boys?

Yes there are differences in special interests. A common interest in females relates to animals, whereas males tend to be more fascinated by more technical related subjects. Boys tend to collect factual information about non-social activities, whereas the girls collect information about people. These interests are often similar to those of typically developing girls and are therefore not seen as unusual. It is not the special interests that differentiate them from their peers but the quality and intensity of these interests and the length of time spent on these. It is essential that we move away from the male stereotype of what constitutes special interests and explore the intensity and duration of the activities engaged in by girls. Girls often become fixated on people who may be real, historical or imagined. It is important to explore the underlying reasons for the interests as imaginary characters may often be linked with a particular play, book or movie the young person has seen or read about.



6. Would you say that girls devise social copying mechanisms, based on their ability to imitate the socially appropriate intersections of their peers, which in fact mean that their difference and difficulties can go unnoticed in a busy classroom or environment?

This is the skill possessed by the girls. They are able to cope with social situations by masking, observing and copying others. They learn social skills through their intellect rather than by instinct or social intuition. Often the girls are passive in their social presentation and are happier when under the radar. They may not ask for help and avoid being the centre of attention. However, some girls excel in role play and drama but often due to their perfectionism will only accept a lead role and can be controlling in their activities.

It is correct that by copying others, professionals do not pick up their social and communication problems. This mimicking and repression of their autistic behaviour is exhausting both mentally and physically. It is not surprising then that they behave impeccably at school and then have complete meltdowns in their safe home environment. This needs to be highlighted for all those working in mainstream education.

Schools need to recognise that it is in the social domain that the girls on the spectrum struggle most.

7. There is growing understanding of how autism impacts or displays differently in women and girls. What do you feel are the differences, do you see them as subtle?

The core difficulties are not gender specific, that is all individuals on the autism spectrum have problems in social interaction, social communication and social imagination, together with a rigid, repetitive pattern of behaviour but we are now aware the behaviour and skills in girls manifest themselves in different ways from boys. This, of course in some ways is a generalisation as there are some girls who behave in a more 'tomboy manner'.

The outward presentation of clothing or toy choice does not necessarily represent the internal cognitive profile. Gender identity in childhood is complex. Many individuals do not think diametrically, that is male or female, but show more gender neutral behaviour. Up to now there has not been a great deal of research into gender-differentiated behaviour manifestations but this is an area of great interest.

8. Is there any practical advice you would give to professionals and parents in supporting women and girls on the autism spectrum that differs from men/boys?

There are books written by parents of girls on the autism spectrum which are both useful and informative. That said, the essential guidelines for supporting boys and girls are basically the same. However, as the girls are often not as obvious regarding overtly challenging behaviour as the boys we need to be mindful of their equally different ways of responding to their typically developing peers. The boys tend to externalise their social problems more readily than females and are, therefore, more likely to be identified as needing support in the classroom.

It is important for parents to be aware that their daughters have learned coping strategies and are more motivated to do so throughout their lives in order to appear more socially typical. Also they are more likely to have a desire to please. Parents and teachers need to be alert, particularly in adolescence when the girls may become depressed or withdrawn. At this time they become more aware of their differences from their peers. Often the gap between their intellectual abilities differs from what they can achieve in their day-to-day life. This gap increases with age. Many of the girls have very low self-esteem and this coupled with their perfectionism makes them extremely vulnerable to social exploitation. Life is hard for all adolescents but it particularly hard for girls on the autism spectrum. We have learned through our clinical work that spending time asking the girls about their views can shed light on how they are struggling to understand the social complexities of life.

9. Are the autism assessment tools used in the diagnostic process a good fit for females?

As mentioned, the current international diagnostic criteria do not give examples of the types of difficulties experienced by girls and women. The autism assessment tools are based on the classification systems. If clinicians continue to use the narrow definitions set out in the classification systems and do not have the experience of working with girls, then the girls will be missed. It is very important to take a holistic view when considering all the developmental disorders including autism. Describing an individual's pattern of skills and difficulties along the developmental domains can not only give a diagnosis but also, more importantly, a detailed profile of the person. A stand-alone diagnosis of autism does not help in planning for the future needs of an individual.

At the Lorna Wing Centre we use the Diagnostic Interview for Social and Communication Disorders (DISCO) which is a semi structured interview which enables a clinician to systematically collect information which not only gives a diagnostic label but also a profile of the person's skills and difficulties. During the training of professionals in the use of the DISCO, emphasis is placed on the different ways in which behaviour is manifested in females compared with males. That is the questions relating to autism are the same for males and females but the examples given for the females will often differ from the males. Due to the complexity of the condition and the very wide ranging and subtle ways in which women and girls present, diagnosis can only be successfully undertaken by an experienced clinician who is able to see and think beyond the lists of criteria in the various classification systems currently available.

There are screening tests for parents to support identification of girls with autism. The questions focus on specifically female presentations of autism. However, this type of assessment should only be used as part of a broader diagnostic assessment. Similarly only using an observational assessment without taking a full developmental history can miss a diagnosis in girls. Within a formal structured setting the girls are able to mask their symptoms and appear to be more socially able than in real-life settings.

10. Does this influence the number who go through the assessment process and do not get a diagnosis first time round?

Girls with a learning disability and a language delay are more likely to be picked up at an early age. Girls who are intellectually able with good language skills are less likely to be picked up in their early years. It is back to clinicians having a good understanding of how to interpret the diagnostic criteria for females. Girls are missed if there is not the understanding of the way their autism is manifested. Often girls are thought to be shy, which is less often attributed to boys. Parents are thought to be over anxious rather than being correct intuitively that their daughter is different. It may take longer to diagnose the girls because of their more subtle social difficulties. Sarah Hendrickx in her book 'Women and Girls with Autism Spectrum Disorder' 2015 gives a clear account of early childhood indicators that are helpful in alerting professionals about early diagnosis.

In our referrals to the Lorna Wing Centre, individuals have often been seen and for whatever reason, have not been given a definite diagnosis. They have been referred with mental health problems with varying diagnoses such as eating disorders, obsessive compulsive disorder, personality disorders, selective mutism, anxiety and depression. More recently, younger girls have been referred where their mothers have recognised the problems they have experienced themselves and do not wish their daughters to go through the same difficulties. These mothers have only recently received a diagnosis for themselves.

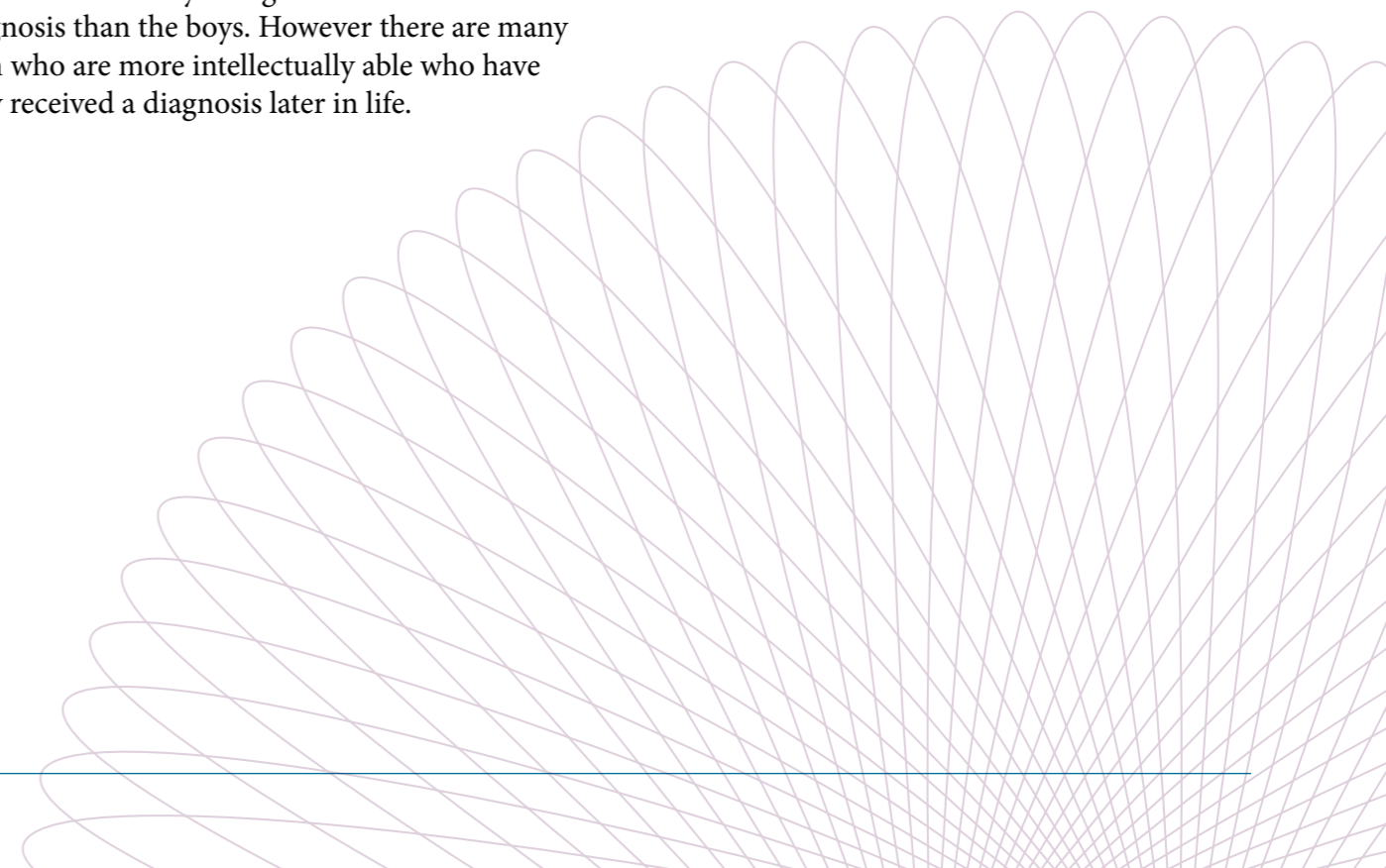
11. Are there statistics in relation to the number of females who do not get a diagnosis on foot of the first assessment (maybe in early years) but do go on to receive a diagnosis later in teenage/adult life?

Various surveys have been carried out looking at time and age of diagnosis. The conclusions are that it is more likely that girls receive a later diagnosis than the boys. However there are many men who are more intellectually able who have only received a diagnosis later in life.

There is now a growing interest in the diagnosis of girls and women on the autism spectrum with an increasing number of papers on this topic. In the past, based on my clinical experience, girls were rarely diagnosed and the majority of women seen had a late diagnosis. This is probably changing due to our increased awareness of the ways girls and women present in their difficulties and strengths.

A timely diagnosis can avoid many of the difficulties women and girls on the autism spectrum experience throughout their lives.

It is never too late to receive an understanding of life's experiences, which then enables the person to get the support needed to maximise their potential and address their emotional well-being.



PRE-SCHOOL CHILDREN WITH SUSPECTED AUTISM SPECTRUM DISORDERS: DO GIRLS AND BOYS HAVE THE SAME PROFILES?

BACKGROUND

Previous research has indicated that there are gender differences in the presentation of autism spectrum disorders (ASD) among children. Research has shown that girls with ASD typically have more problems with communication, compared with boys of the same age, but that boys show more repetitive behaviours than girls. This research project aimed to explore the relationship between gender and age at diagnosis at pre-school age, given that previously there have been few studies exploring this.

RESEARCH AIMS

The study set out to examine whether or not pre-school girls and boys, less than three years of age, have the same clinical, developmental, social and language profiles. The researchers identified three main aims, which were to:

- Describe the potential differences in a sample of young 1-3 year old girls with ASD, and compare them with those of age and developmentally matched boys with ASD.
- Analyse the correlation between results obtained in different developmental areas' test results, and compare them across genders.
- Identify avenues for further research in the field.

RESEARCH METHODS

The study compared the gender differences between 20 girls, aged between one year, eight months and three years, nine months, and 20 boys. The girls were matched with boys for comparison by chronological and developmental age.

The children were recruited at autism general population screenings, performed at pre-school age, and had been referred to the Child Neuropsychiatry Clinic (CNC), Gothenburg, for assessment and given a diagnosis of ASD.

All 40 children underwent a number of comprehensive neuropsychiatric assessments. These were:

- Medical-neurological-psychiatric examination of the child.
- Child and family medical/psychiatric history taken from the parent.
- Griffiths' Developmental Weschsler Preschool and Primary Scale of Intelligence, third edition.
- Vineland Adaptive Behaviour Scales.
- MacArthur Communicative Development Inventory.
- Diagnostic Interview for Social and Communication disorders (DISCO-11).
- Pre-school observation.
- Autism Diagnostic Observation Schedule (ADOS).
- Children's Global Assessment Scale (CGAS).

All test results were then evaluated in relation to clinical judgement.

All the various assessments were carried out independently of each other and the research clinicians remained blind to the other assessment results until a consensus diagnostic case conference was held after all the assessments had taken place.

RESEARCH FINDINGS

The research found that there was no significant difference between the girls and boys on any variable tested, i.e. regarding clinical diagnosis (e.g. atypical autism, Pervasive Developmental Disorder, Asperger Syndrome, etc.), cognitive level, repetitive behaviours, adaptive behaviour, comprehension, expressive language level, ADOS severity score or overall global functioning. There were strong correlations between results obtained in different developmental areas across both genders.

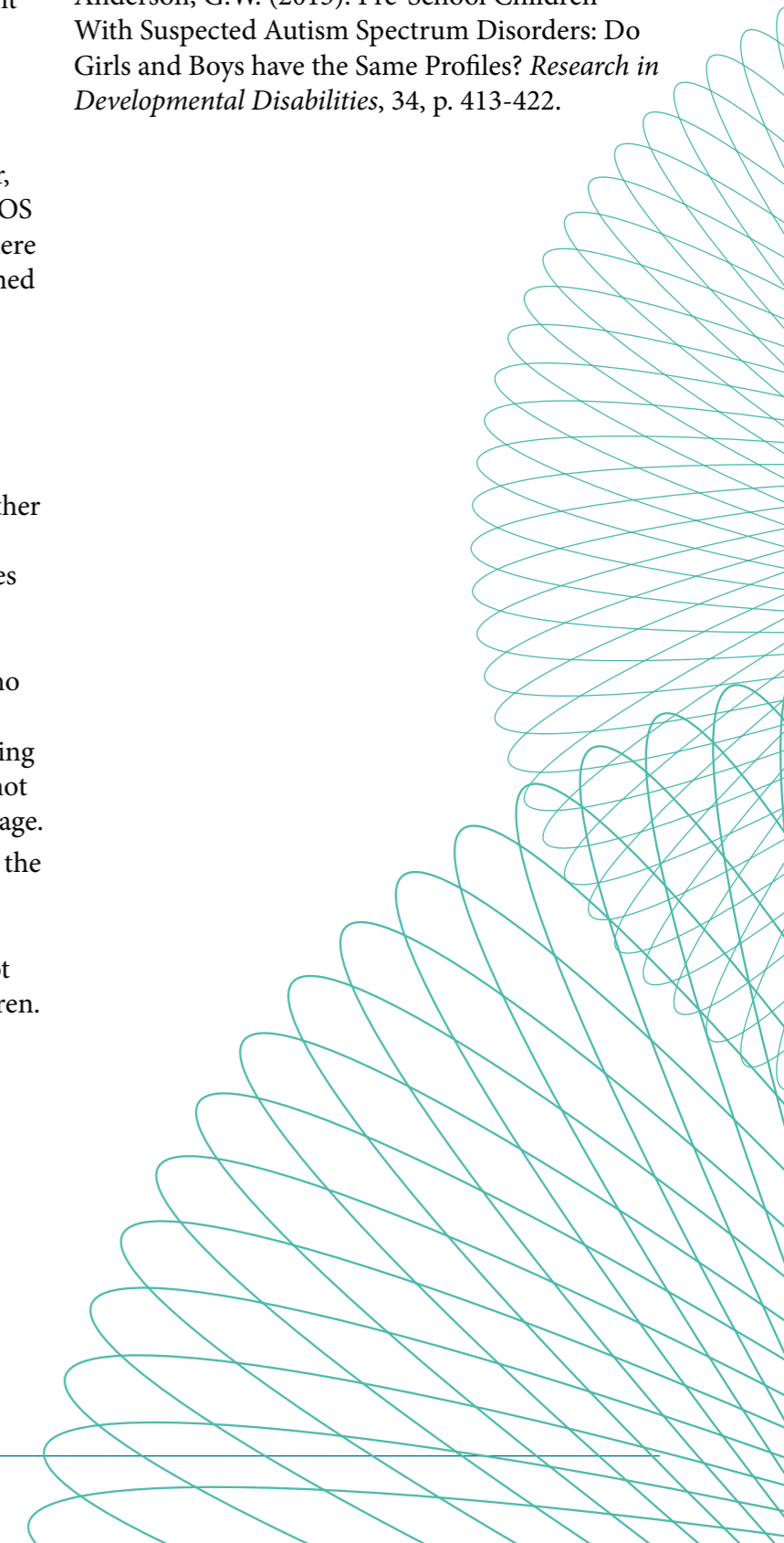
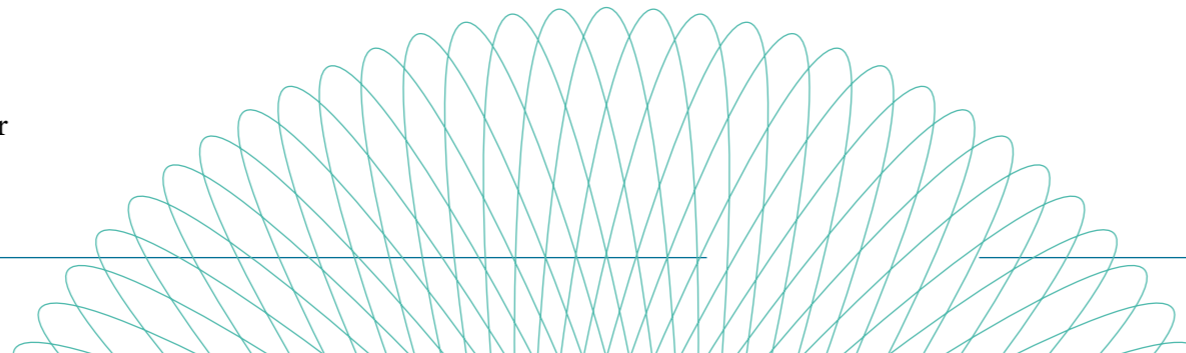
IMPLICATIONS FOR PRACTICE

(by the authors)

- The findings of this research suggest that either previous studies highlighting clear gender differences may have overrated discrepancies between boys and girls with autism, or that there may be a number of girls, not yet identified in early years ASD screenings, who receive a diagnosis later. The researchers suggest that the latter is most likely, suggesting that the screening tools currently used are not identifying all girls with ASD at pre-school age.
- Given the relatively small sample size of 40, the researchers highlight the need for more research to take place before it can be established that the clinical phenotype is not different across genders in pre-school children.

Full Reference

Anderson, G.W. (2013). Pre-School Children With Suspected Autism Spectrum Disorders: Do Girls and Boys have the Same Profiles? *Research in Developmental Disabilities*, 34, p. 413-422.



GIRLS ON THE AUTISM SPECTRUM IN THE CLASSROOM: HIDDEN DIFFICULTIES AND HOW TO HELP

BACKGROUND

Victoria Honeybourne is a Senior Advisory Teacher with Speech Language and Communication Needs. As a teacher of pupils with special educational needs and as a woman diagnosed with Asperger's Syndrome herself, she wanted to explore the educational experiences of girls and women with autism.

RESEARCH AIMS

The aim of this study was to investigate how girls with autism experience the school environment, looking at their strengths and difficulties and how they felt school policies, practices and environments could be improved.

RESEARCH METHODS

The 67 participants were all female, with a diagnosis on the autism spectrum (including Asperger's Syndrome and High Functioning Autism). Respondents were between the ages of 14 and 50+ years.

The participants were asked the following:

- What were the positive aspects of your school experiences? (Consider both primary and secondary school, academic and/or extracurricular areas you enjoyed, your strengths, specific events or situations you enjoyed.)
- What were the negative aspects of your school experiences? (Again consider both primary and secondary school, any negative impact of your autism, areas you found especially difficult.)
- What advice would you give teachers / educators / school staff to help them meet the needs of girls with autism?
- What advice would you give younger girls with autism to help them make the most of their school experience?

Data was collected through face to face interviews, emails, online surveys and through Facebook groups. Those who were interviewed face to face were probed for more detail. Not all participants answered every question.

RESEARCH FINDINGS

What were the positive aspects of your school experiences?

- The majority of the participants reported experiences such as specific lessons / topics they excelled in, how they enjoyed following the rules and being able to remember facts. One participant reported: *"I found it easy to learn facts and remember things. I loved the routine of having a timetable."*

What were the negative aspects of your school experiences?

- The participants reported negative experiences with friendship, communication, learning, interpreting the world and feeling misunderstood.
- Friendship: In almost all cases the participants reported feelings of isolation and loneliness which in some cases led to depression, self-harm or school refusal. Many found break and lunch times particularly difficult.
- Communication: Difficulties were expressed with speech and written work, group discussion and social communication.
- Learning: Several participants said they found school work too easy, others reported they needed a different way of being taught while others said they had their own way of learning.
- Interpreting the world: Several participants spoke about sensory issues, others commented on how they struggled with authority, others discussed fairness and equality and needing rules to make sense. Some participants spoke about the need for routine and structure.

- Feeling misunderstood: Many respondents discussed feeling misunderstood by both peers and staff. Words that were mentioned included 'shy', 'quiet', 'overlooked' and 'invisible'.

Respondents' suggestions for schools to help pupils feel understood included

- Staff should be patient.
- Staff should emphasise with the positive aspects of girls' nature.
- Staff should give girls with autism time and space.
- Provide counsellors.
- Educate the girls about autism.
- Build confidence and self-esteem.

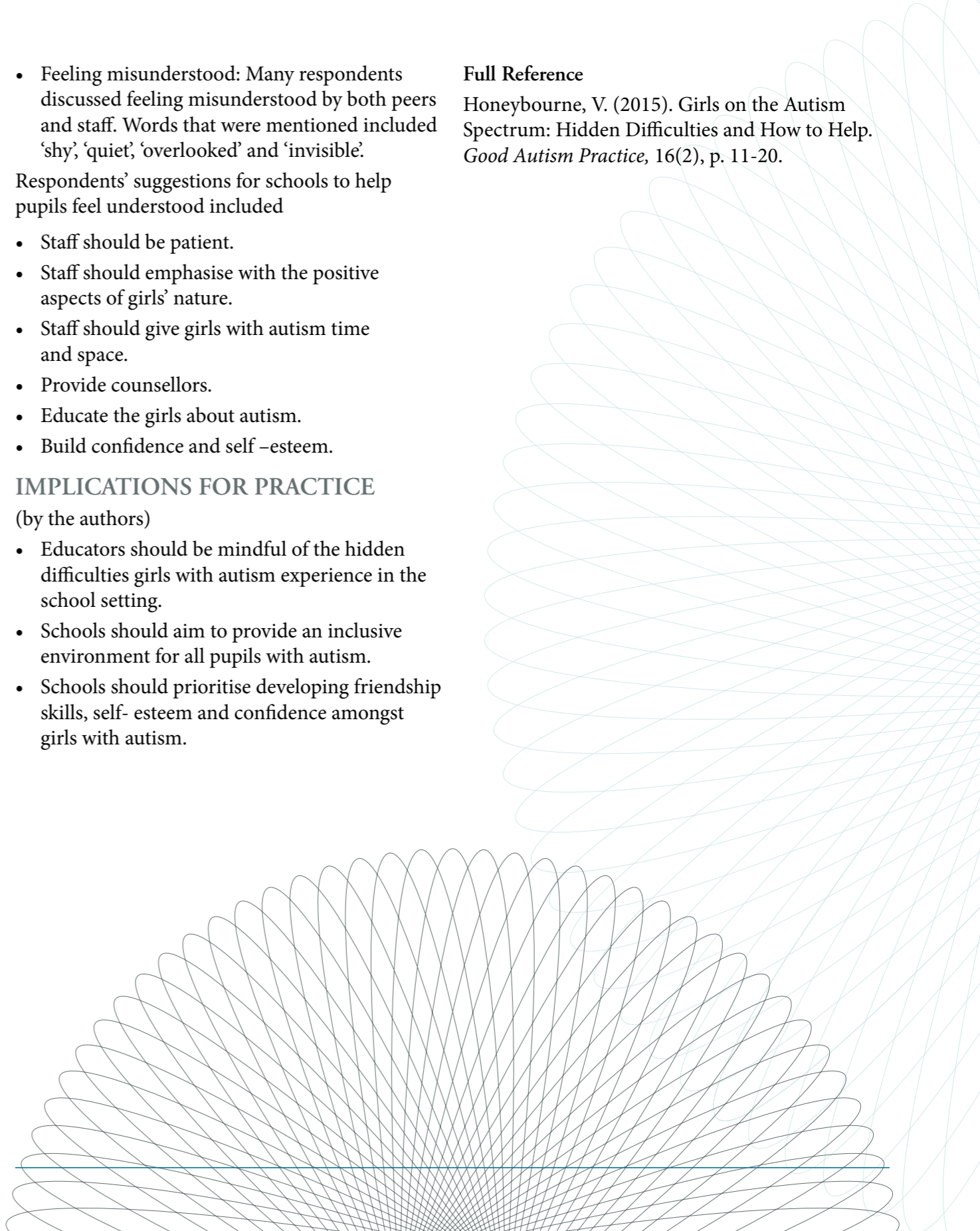
IMPLICATIONS FOR PRACTICE

(by the authors)

- Educators should be mindful of the hidden difficulties girls with autism experience in the school setting.
- Schools should aim to provide an inclusive environment for all pupils with autism.
- Schools should prioritise developing friendship skills, self-esteem and confidence amongst girls with autism.

Full Reference

Honeybourne, V. (2015). Girls on the Autism Spectrum: Hidden Difficulties and How to Help. *Good Autism Practice*, 16(2), p. 11-20.



PROMOTING PEER ACCEPTANCE FOR FEMALE PUPILS WITH AUTISM WITHIN A MAINSTREAM EDUCATION SETTING

BACKGROUND

Individuals with autism experience high levels of peer victimisation and rejection. In Australia, the Disability Standards for Education Act (2005) protects the rights of children with a disability to be given the same opportunities as those without a disability within education and training. Increased public awareness and protective legislation of this has spread across western countries and has led to a rise in the number of children attending mainstream education. This is particularly true for those with a diagnosis of High Functioning Autism (HFA) or Asperger's Syndrome.

There is, however, a common misunderstanding that because individuals with HFA are academically able they can manage effectively within inclusive educational environments. A lack of evidence, however, suggests that these children cannot make gains socially within a mainstream setting without targeted intervention or support.

RESEARCH AIM

The researchers aimed to investigate the effect of a multi-session, peer, anti-stigma programme on the knowledge, attitudes and behavioural intentions of typically developing peers towards females with high functioning autism.

RESEARCH METHOD

Participants consisted of seventh, eighth and ninth-grade students (N=273). Two eighth grade classes (N=48) were randomly assigned to the intervention condition. The remaining participants were allocated to a no-intervention peer condition (n=56). All participants were female and the median age in the intervention group was 13, while the median age for the no-intervention group was 12 years of age.

All seventh and ninth grade classes were allocated to a no-intervention, non-peer condition to form a control group.

The programme involved eight, 50 minute sessions and was entitled, 'Understanding Our Peers'. Detailed programme outline is contained in the study's appendices. Participants were also asked to complete a web-based online activity after each session as homework.

The following measures were used to assess knowledge, attitudes and behavioural intentions of typically developing peers towards females with high functioning autism.

- The Autism Knowledge Questionnaire-Revised (AKQ-R).
- The Adjective Checklist (ACL).
- Shared Activities Questionnaire-Revised (SAQ-R).
- Similarity Rating Form-Revised (SRF-R).
- Perceived Responsibility Questionnaire-Revised (PRQ-R).
- Student Interaction Questionnaire-Revised (SIQ-R).

Measurement was taken before the programme began, immediately after the session and at follow up, during the next academic term.

RESEARCH FINDINGS

Overall the results indicated that the eight session programme impacted on the knowledge, attitudes and behavioural intentions of typically developing peers towards females with high functioning autism. Specifically peers in the intervention group were found to have more positive attitudes, knowledge and slightly improved behavioural intentions towards peers with high functioning autism. The no-intervention group showed no change in knowledge, however, the level of change in attitudes in the no-intervention group was equivalent to those who received the intervention.

While there was also an increase in positive attitudes towards peers with autism within the control group, there was no increase in knowledge and unexpectedly poorer behavioural intentions.

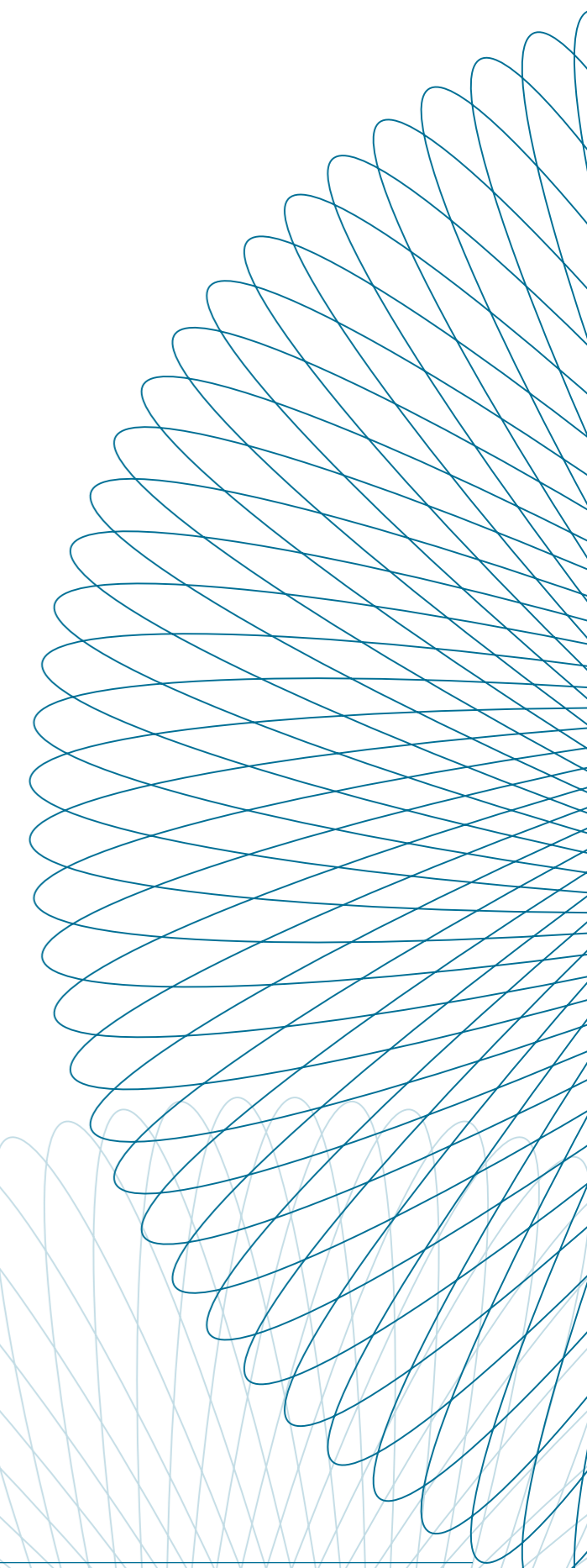
IMPLICATIONS FOR PRACTICE

(by the authors)

- The researchers posit that the findings highlight that typically developing pupils do not possess the knowledge and skills necessary to positively interact with female students with autism.
- The findings indicate evidence of the efficacy of a peer programme aimed to increase the knowledge, attitudes and behavioural intentions towards female pupils with autism. Due to the high level of peer rejection reported for pupils with autism within mainstream settings (Humphrey & Lewis, 2008) this may be an effective tool to promote peer acceptance.

Full Reference

Ranson, N.J. and Byrne, M.K. (2014). Promoting Peer Acceptance of Females with Higher-Functioning Autism in a Mainstream Education Setting: A Replication and Extension of the Effects of an Autism Anti-Stigma Program. *Journal of Autism and Developmental Disorders*, 44(11), p.2778-2796.



SEX DIFFERENCES IN THE TIMING OF IDENTIFICATION AMONG CHILDREN AND ADULTS WITH AUTISM SPECTRUM DISORDERS

BACKGROUND

Autism Spectrum Disorders (ASD) to include autism, Asperger's Syndrome and Pervasive Developmental Disorder Not Otherwise Stated (PDD-NOS) have historically had a consistent male predominance ranging from 4:1 among those with autism to 9:1 among those with Asperger's Syndrome. Early identification in terms of a diagnosis is crucial for the overall well-being, the timing of educational interventions and early treatment and the beginning of family centred care. These can result in better communication skills, lower rates of behaviour problems and anxiety and a reduction in stress levels for parents. Previous studies have failed to find sex differences in age of ASD diagnosis but these studies lacked statistical power and were not based on large scale samples.

RESEARCH AIMS

The aim of the study was to examine sex differences in the timing of identification of ASD in males and females using a large European cohort.

RESEARCH METHODS

Survey data were collected from 2,275 males and females from the Netherlands during 2012 who had a diagnosis of autism, Asperger's Syndrome or PDD-NOS. The sample included children (0-18 years) and adults (18-85 years). Respondents were predominantly male (81%) with only 19% of the respondents being female. Survey data covered all 12 provinces in the Netherlands and the distribution of age, subtypes of ASD and cognitive ability and gender were similar to previous international epidemiological studies. Surveys were completed either by the parents/next of kin or the individual themselves. Some surveys were excluded due to large amounts of missing data, leaving a sample of 2,084 for analysis.

A series of stepwise linear regression analyses were carried out using age of diagnosis as the dependent variable in each model. Current age was entered first in the model followed by sex and then the age where the parents first showed concern. Child and adult groups were analysed separately.

RESEARCH FINDINGS

Based on all respondents together (child and adult) the average time between first signs and diagnosis was longer for females compared to males (2.3 years compared to 1.9 years). Due to the influence of adults being diagnosed much earlier than the children, the remainder of the results were stratified into separate child and adult groups where current age was controlled for in both groups.

In the child group, females with Asperger's Syndrome had a 1.8 year delay in age at diagnosis but no gender difference was found for females with autism or PDD-NOS. In the adult group, females with autism had a 4.3 year delay in age of diagnosis but no gender difference was found for females with Asperger's Syndrome or PDD-NOS.

There was a wide variation in age at diagnosis in the adult group with 300 diagnosed younger than 12 years, 142 diagnosed between 12 and 18 years and 730 diagnosed older than 18 years.

No gender differences were found in the age of diagnosis of adults when analysed according to whether they were diagnosed as children (0-12 years), adolescents (12-18 years) or adults (>18 years).

IMPLICATIONS FOR PRACTICE

(by the authors)

- This study confirms that girls are identified later than boys among children with Asperger's Syndrome but found no such delay for female children with autism or PDD-NOS. In contrast, in the adult group, females with autism were diagnosed later than males but no delays were found for female adults with Asperger's Syndrome or PDD-NOS. The age at first parental concern was not related to any sex differences.
- The later diagnosis of Asperger's Syndrome in girls may be related to the late general timing of diagnosis in Asperger's Syndrome, on average at eight years of age, one year later than children with PDD-NOS and three years later than children with autism, who were diagnosed on average at around five years of age.
- More adults in this sample were diagnosed according to DSM-III which was more specific than the DSM-III-R. Autistic disorders may have been less suspected in girls decades ago, just like Asperger's Syndrome is suspected less now. In fact with the current DSM-5 classification, PDD-NOS and Asperger's Syndrome have been integrated into one Autism Spectrum Disorder making it harder to identify gender disparities. Diagnostic instruments need to be developed that are sensitive to the female presentation of autism.

Full Reference

Beeger, S., Mandell, D., Wijnker-Holmes, B., Venderbosch, S., Rem, D., Stekelenburg, F. and Koot, H.M. (2013). Sex Differences in the Timing of Identification among Children and Adults with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 43, p. 1151-1156.

SEX DIFFERENCES IN PRE-DIAGNOSIS CONCERNS FOR CHILDREN LATER DIAGNOSED WITH AUTISM SPECTRUM DISORDER

BACKGROUND

Due to the absence of an intellectual impairment, girls are quite often diagnosed significantly less than their male counterparts. This study explored possible reasons why autism may be more difficult to detect in girls based on concerns by the carer during the pre-diagnosed period.

RESEARCH AIM

The primary aim of this study was to investigate whether there were sex differences in carers' pre-diagnosis concerns for children who would later receive a diagnosis of autism. Three additional secondary aims were to explore carers' perspectives on (a) the response received from professionals regarding carer concern, (b) whether girls engage in social strategies which may impact their overt social presentation and (c) the types of obsessional interests displayed by girls versus boys. This study specifically focused on children who were not diagnosed until school-age in order to explore how these factors may have made it more difficult to detect autism.

RESEARCH METHOD

Several criteria were identified for participation in this study: the carer was required to have a child who had a current diagnosis of autism, had no intellectual disability, was diagnosed after five years of age and was currently aged between five and 18 years of age. Out of 187 people who completed the online questionnaire 157 were eligible for inclusion.

Participants completed a 40-item online survey comprised of a combination of multiple-choice and free-response questions.

RESULTS

This study used a backward step logistic regression to determine what group of key early signs of autism best predicted sex. It also used logistic regression equations to calculate the predicted odds for each level of all significant predictors.

Pre-diagnosis concerns for children later diagnosed with autism:

Parents were asked to report on the very first concern they held for their child, the most common initial concern for the child's development was difficulties with behaviour (girls: 39.7%; boys: 21.6%). For girls other than behaviour, parental reports of first concerns were evenly distributed across other options. Whereas for boys, 21.6% reported medical issues to be their first concern and 20.5% were first concerned with language development.

In regard to behaviour, responses were coded as either externalising (hitting, yelling, controlling play) or internalising (withdrawn, avoidance, remaining passive). Reporting the primary concern as externalising behaviour was predictive of being female.

Within the questionnaire 17 items pertained to concerns commonly seen as early signs of autism; exploratory analysis was used to identify key predictors of sex, of which there were five. Logistic regressions, controlling for age, identified that four items significantly predict sex:

Imitation complexity: over 70% of girls were reportedly able to engage in complex imitation compared to 34% of boys, based on odd ratios if the carer reported the child had engaged in complex imitation during the pre-school years they were over five times more likely to be girl rather than a boy.

Interest in parts of mechanical objects: girls were rated as having little or no interest in parts of mechanical objects (girls: 48%; boys: 15%), whereas boys were most commonly rated as 'fascinated', 55% as compared to 26% of girls.

Desire to be liked: based on carer perception girls were more likely to have an unusually strong desire to be liked by peers, almost a quarter of girls (22%) compared to only 10% of boys.

Vocabulary: boys were reported as more likely to present with below average vocabulary (42%) as compared to girls (28%). Responses indicated that girls were rated as having above average vocabulary in the pre-school years (46%).

Responses from professionals:

Responses given by medical professionals did not significantly predict sex. Parental responses indicated that 33% of participants experienced 'ambivalence/no concern' as the initial response from a medical professional, 36% also had another diagnosis queried as the initial response.

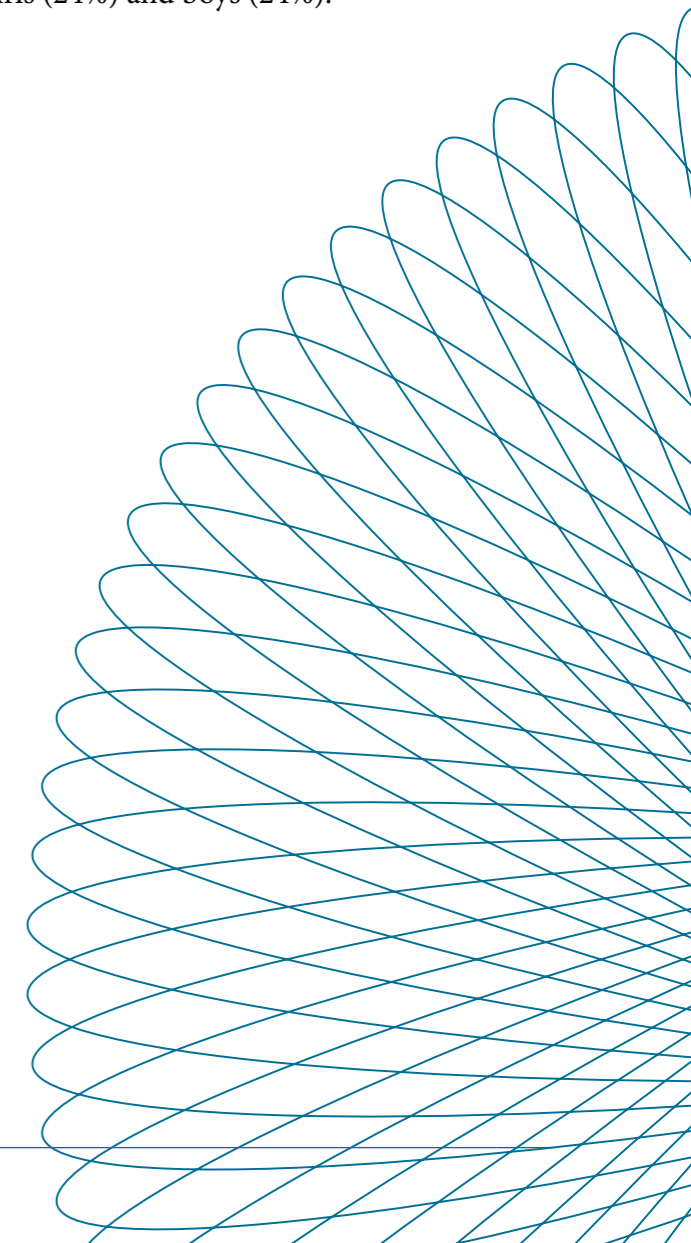
Timing of teacher concern:

The results showed that reported timing of concern expressed by teachers predicted sex. If it was reported that no teacher ever expressed concern for the child's development, the child was over 13 times more likely to be a girl. Within this sample, no teacher had reportedly ever expressed concern for the behaviour or development of 25% of the girls. This was rare for boys (7%) with majority of boys (62%) having a teacher report concern during the pre-school years.

Strategies used for navigating social situations:

The results show that social compensatory strategies significantly predicted sex. If a preference for mimicking as a social strategy was reported the child was over 16 times more likely to be a girl; with 37% of girls reported to use mimicking in this study. Mimicking was the primary strategy for only 10% of boys.

Isolating from play or remaining a passive observer was the primary strategy for 30% of boys compared to 9% of girls. Engaging in conversation with adults was another common strategy for both girls (24%) and boys (24%).



SEX DIFFERENCES IN TYPE OF RESTRICTED/REPETITIVE BEHAVIOURS:

Carers were asked about the most concerning type of obsessions/restricted interest held by the child during the pre-school years. The results showed that fascination with wheeled toys was strongly predictive of being a boy (59%). Very few girls reportedly displayed this fascination (5%).

In contrast a strong predictor for girls was fascination with seemingly random objects (33%) and obsessional/repetitive behaviour with toys (39%). In comparison these were rare fixations for boys (random: 6%; toys: 14%).

IMPLICATIONS FOR PRACTICE

(by the authors)

- The ability to mimic social interactions and attempts to actively connect with peers (e.g. unusually strong desire to be liked) may complicate the detection of potential deficits in the girls' underlying social understanding.
- The researchers were surprised to find that externalising behaviour was of greater concern for girls than boys, with externalising behaviour the main concern reported for half of girls and only a quarter of boys. This finding may also reflect that girls' atypical development is more likely to be noticed when their behaviour is more difficult to manage.
- Within this study teachers were less concerned with girls than boys, other studies indicate that boys with autism showed more problematic behaviour at school. The researchers in this study suggest that home and school presentations are likely starkly different for girls with autism. Possible conflicting reports between carers and teachers would likely further complicate a clinician's ability to determine whether exploration of autism diagnosis is warranted.

- The study suggests that girls present with fewer restricted/repetitive behaviours to boys. Whereas boys' early restricted behaviour tended to be the non-functional use of wheeled toys, girls were reportedly more likely to show obsessional interests with toys or seemingly random objects. It is suggested that girls' interests may be less intense than boys' which may mean they are less disruptive to the family and therefore more difficult to detect as a sign of autism.
- A key issue is improving professionals' understanding of how symptoms of autism may present differently in girls rather than the presence or absence of core symptoms.

Full Reference

Hiller, R.M., Young, R.L., and Weber, N. (2015). Sex Differences in Pre-Diagnosis Concerns for Children Later Diagnosed with Autism Spectrum Disorder. *Autism*, p. 1-10.

AUTISM SYMPTOMS AND INTERNALIZING PSYCHOPATHOLOGY IN GIRLS AND BOYS WITH AUTISM SPECTRUM DISORDERS

BACKGROUND

The literature regarding sex differences and ASD is mixed. Some theorists suggest that being female confers protection against autism traits, inferring that females diagnosed with ASD present with milder symptoms than males with an autism diagnosis. Others have postulated that girls with ASD are more severely impaired than boys with ASD. However, not all studies have documented sex differences with some investigators finding comparable levels of impairment in boys and girls with autism across a range of samples.

Research has also demonstrated that levels of depression in adolescent females is greater than that in males. Additionally, young people with autism demonstrated increased internalising psychopathology relative to typically developing individuals. Therefore, an important issue in the ASD population is whether girls with ASD are at an elevated risk for affective disorders.

RESEARCH AIMS

The primary aims of the current paper were (1) to investigate whether the clinically-referred high-functioning sample of boys and girls differed in ASD symptoms using independent assessments of language, social, and repetitive behaviour symptoms, (2) to assess whether girls with ASD are more impaired than typically developing (TYP) girls in terms of social and language abilities and (3) to investigate whether girls with ASD are at greater risk for internalising problems than TYP girls and boys with ASD.

RESEARCH METHOD

Seventy six children (aged 8-11yrs) and adolescents (aged 12-18yrs) participated in this study. Four age-matched groups were formed: girls with ASD (n=20); boys with ASD (n=19); typically developing girls (n=19); typically developing boys (n=17). The ASD groups were matched on IQ. Approximately half of each group were children and half were adolescents. Participants could not have a diagnosis of depression, anxiety disorders, ADHD, Fragile X, Tourette's or seizure disorders.

The following Qualification Measures were used:

- *Weschler Abbreviated Scale of Intelligence (WASI)* was used to provide a short and reliable assessment of intelligence.
- *Autism Diagnostic Observation Schedule – Generic (ADOS-G)* was used to confirm diagnosis.
- *Social Communication Questionnaire (SCQ)*: was completed by participants' parents to evaluate communication and social skills.

The measures used to assess autism symptoms included the Social Responsiveness Scale (SRS), Children's Communication Checklist – 2nd Ed (CCC-2) and the Repetitive Behaviour Scale-Revised (RBS-R).

The following measures were used to assess internalising psychopathology: Behaviour Assessment Scale for Children (BASC2) and the Children's Depression Inventory (CDI).

RESEARCH FINDINGS

Findings regarding phenotypic differences between boys and girls with ASD are mixed. Girls with ASD were found to be more impaired than TYP girls but they did not differ from boys with ASD in autism symptoms. In adolescence, results showed that girls with ASD had higher internalising symptoms than boys with ASD and TYP girls, and higher symptoms of depression than typically developing girls. Girls with ASD appear to be at increased risk for affective symptoms in the teen years.

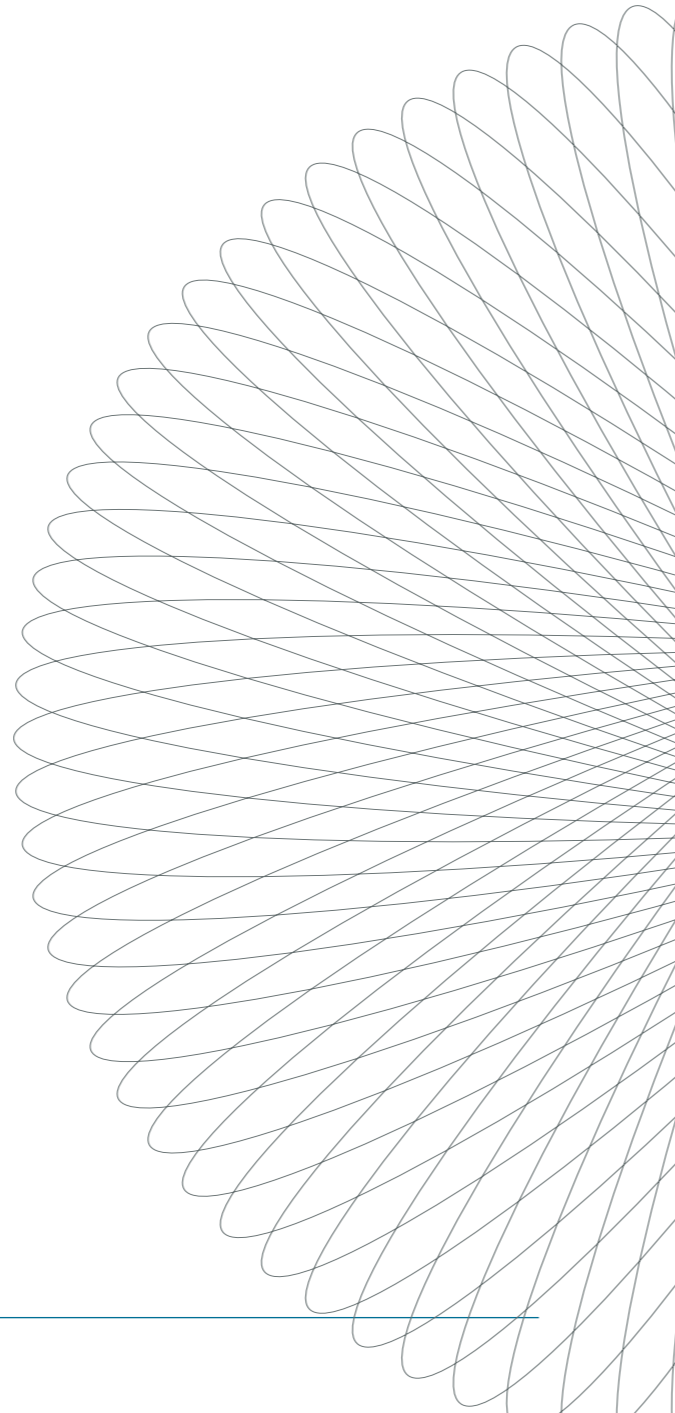
IMPLICATIONS FOR PRACTICE

(by the authors)

- Girls with ASD appear to be at increased risk for developing affective symptoms in adolescence. This suggests the need for parents and school teams to access education and training on signs and symptoms associated with affective disorders in order to seek help at the earliest possible stage.
- Developing and implementing effective interventions – cognitive, behavioural and psychotropic - to address internalising symptoms in this high risk population of girls is essential to minimise the potential effects of outcomes associated with adolescent depression, including risk for affective disorders, psychiatric hospitalisation and suicidal ideation.

Full Reference

Solomon, M., Miller, M., Taylor, S.L., Hinshaw, S.P., and Carter, C.S. (2012). Autism Symptoms and Internalizing Psychopathology in Girls and Boys with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 42, p.48-59.



ASD IN FEMALES: ARE WE OVERSTATING THE GENDER DIFFERENCE IN DIAGNOSIS?

BACKGROUND

Research to date supports that an autism spectrum disorder (ASD) is more typically diagnosed in males than females, with ratios ranging from 4.3:1 to 16:1, a range that would seem to be tempered by intellectual ability. This study proposed that ASD may be under identified in females without a co-occurring intellectual impairment due to a range of subtle gender differences in symptom manifestation and gender imbalances in ASD research which may contribute to biasness in assessment tools and diagnostic practices.

RESEARCH AIMS

The aims of this research are to explore theoretically if a diagnostic under-identification exists in girls aged 18 or younger, who do not present with a co-occurring intellectual disability (ID). In addition, this study explores the role that sociocultural influences may play on the gender differences in diagnosis, and also the factors which may contribute to possible under-identification in females.

RESEARCH METHODS

The authors reviewed and summarised existing literature on the gender difference in core and co-occurring diagnosis of ASD.

RESEARCH FINDINGS

To date the gender difference in diagnosis has been primarily explained by three models; the brain differences model (BDM), the liability/threshold model (LTM), and the greater variability model (GVM), although it must be noted that none of these models has had consistent empirical support. The BDM proposes that the difference in male and female brain increases males' vulnerability to ASD given that ASD characteristics derive from the extreme form of the male neurodevelopmental pattern. Females, on the other hand, may be less vulnerable due to their inherent empathic and social proficiencies. Similar to the BDM, the GVM asserts that males are more vulnerable to ASD given their broader genetic variability whereas a particular type of pathology may underlie autistic traits in females. The LTM however, puts forward the theory that while both males and females are equally susceptible to ASD, females have an inherent higher threshold to the disorder.

The authors posit that where within any clinical condition, there exists an over-representation in one gender, the presence of bias in diagnostic and sampling criteria must be considered. From the existing literature a number of factors have been identified that may contribute to the gender difference in diagnosis of ASD:

- A higher number of males are referred to clinics or specialised services due to their presentation, for e.g. engaging in disruptive behaviours.
- Females may need to exceed a higher threshold of severity than males to receive a diagnosis.
- Very few studies take into account differences in ID when comparing females and males. Equally only a small percentage of studies examine dependent variables separately for males and females.

- Most research has been based on convenience samples from specialised clinics which have a disproportionate representation of males.
- Population-derived data have seldom been used to examine gender differences in ASD symptoms.
- The widespread use of health and educational records to identify cases for epidemiological studies means that females with ASD are likely to be missed as a result of the differences in presentation between the genders.
- Differences in phenotypic expression between the two genders, where the criteria for diagnosis is more characteristic of one gender, can also lead to underrepresentation of the less frequently diagnosed gender. This in turn can lead to biases in diagnostic criteria as the criteria are based on the observed symptoms in the predominant gender. Of concern also is the potential for clinician bias due to clinical expectancies.
- A potential exists also for gender bias in the assessment tools used to diagnose ASD due to the predominance of male samples included in the development of said tools. Previous studies have found that this may result in a failure to diagnose many affected females.
- Females with ASD (without ID) may exhibit less pronounced social deficits due to conformation to culture-based gender role expectations and the internalisation of problems.
- Peer groups, including protective female peers, may play a significant role in disguising social deficits or shaping the behaviour of females with ASD.
- Gender-based expectations may serve to disguise social difficulties or developmental delays through their being interpreted as shyness or immaturity.
- Due to its impression on behaviour, sociocultural influences may also impact upon referral rates and a clinician's ability to accurately identify and diagnose ASD, as the individual may not represent the prototype of the condition.
- Gendered behaviour is also shaped by parents, and for females with ASD their close relationship with their mother may help to improve their empathising or conversational abilities.
- Across studies females tend to present with less repetitive and stereotyped behaviours, and fewer restricted interests, than males which may also contribute to under identification of ASD in females.

The authors also posit that sociocultural influences and intrapersonal processes may impact upon the behaviour of females with ASD (without ID) and that these influences, in addition to genetic and biological processes, may serve to mask the more typical presentation of individuals with ASD. The existing literature looks at how the sociocultural influences of school, home, community and ethnicity form a basis from which behaviour is moderated by gender. Within this research a number of such influences have been identified:

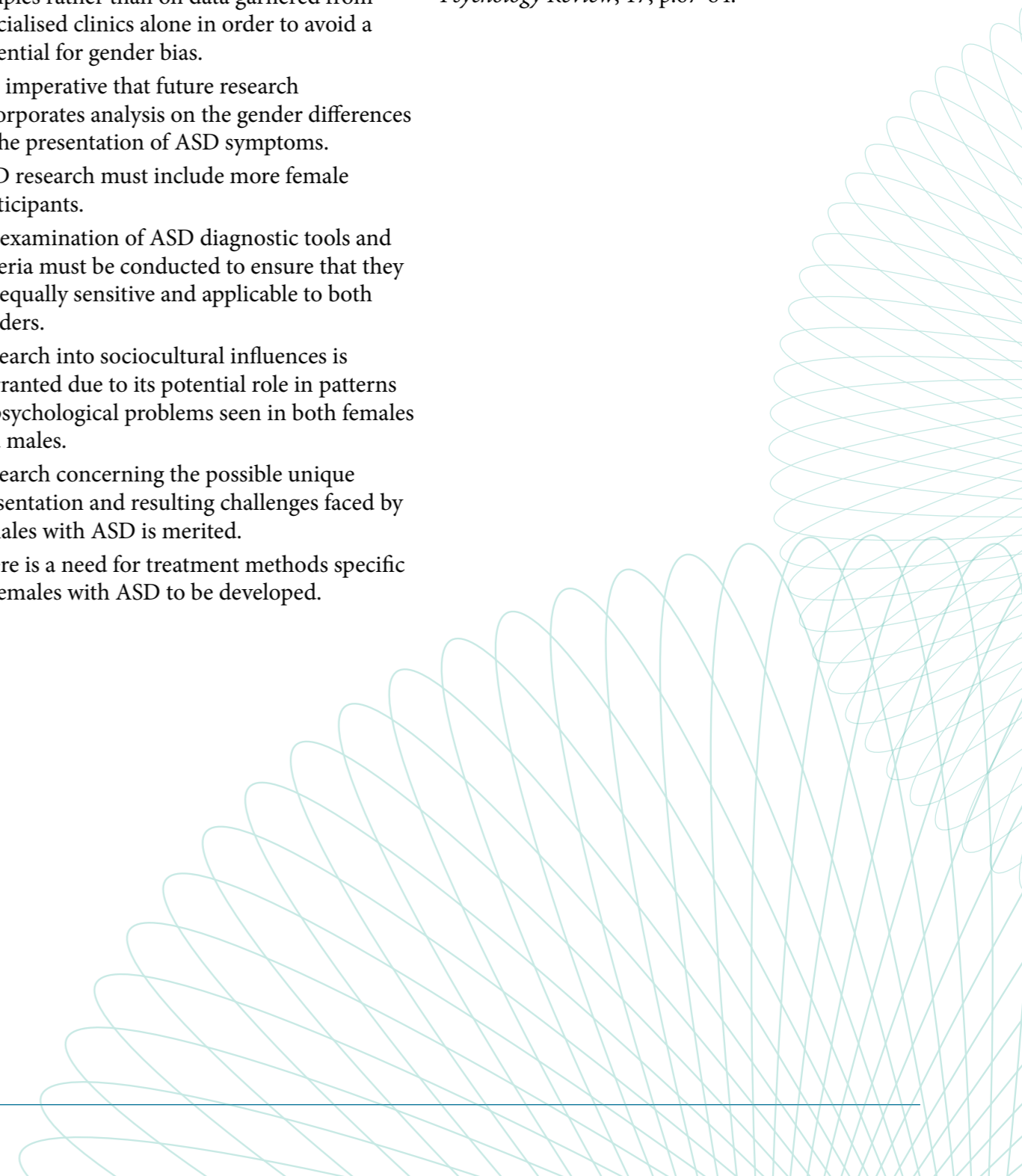
IMPLICATIONS FOR PRACTICE

(by the authors)

- It is important that gender comparisons are based on representative general population samples rather than on data garnered from specialised clinics alone in order to avoid a potential for gender bias.
- It is imperative that future research incorporates analysis on the gender differences in the presentation of ASD symptoms.
- ASD research must include more female participants.
- An examination of ASD diagnostic tools and criteria must be conducted to ensure that they are equally sensitive and applicable to both genders.
- Research into sociocultural influences is warranted due to its potential role in patterns of psychological problems seen in both females and males.
- Research concerning the possible unique presentation and resulting challenges faced by females with ASD is merited.
- There is a need for treatment methods specific to females with ASD to be developed.

Full Reference

Kreiser, N.L. and White, S.W. (2014). ASD in Females: Are We Overstating the Gender Difference in Diagnosis? *Clinical Child and Family Psychology Review*, 17, p.67-84.



SEX DIFFERENCES IN AUTISM SPECTRUM DISORDER: EVIDENCE FROM A LARGE SAMPLE OF CHILDREN AND ADOLESCENTS

BACKGROUND

Previous research has identified differences in the prevalence, IQ and core features of autism (e.g. repetitive behaviour, communication difficulties) depending on whether a person is male or female.

RESEARCH AIMS

This study aimed to investigate the presence and stability of ASD sex differences throughout childhood and adolescence.

RESEARCH METHODS

A total of 325 children and adolescents, 52 female and 273 male, aged 3 – 18 years with a diagnosis of autism were recruited from a clinic assessing high functioning autism (mean verbal IQ = 92.6) over a ten year period (1999 – 2009). The parents and teachers of the children and adolescents completed interviews and questionnaires with an experienced child psychiatrist or clinical psychologist.

Measures used with the parents and teachers included:

- The Developmental, Dimensional and Diagnostic Interview.
- The Autism Diagnostic Observation Schedule.
- The Strengths and Difficulties Questionnaire.

Using the measures listed above, the researchers focused on the sex differences regarding the core and associated features of autism.

RESEARCH FINDINGS

In the areas of intellectual ability, reciprocal social interaction, communication, visio-spatial impairment, gross motor skills, auditory sensitivity and feeding difficulties, there was no difference found between male and female participants.

Males were reported to have more repetitive and stereotyped behaviours than females.

Females were reported to have better fine motor skills than males.

Parents reported higher levels of emotional symptoms for females, however teachers reported higher levels for males.

In school, males had a higher total problem score, particularly greater difficulties with hyperactivity/inattention and prosocial behaviour.

IMPLICATIONS FOR PRACTICE

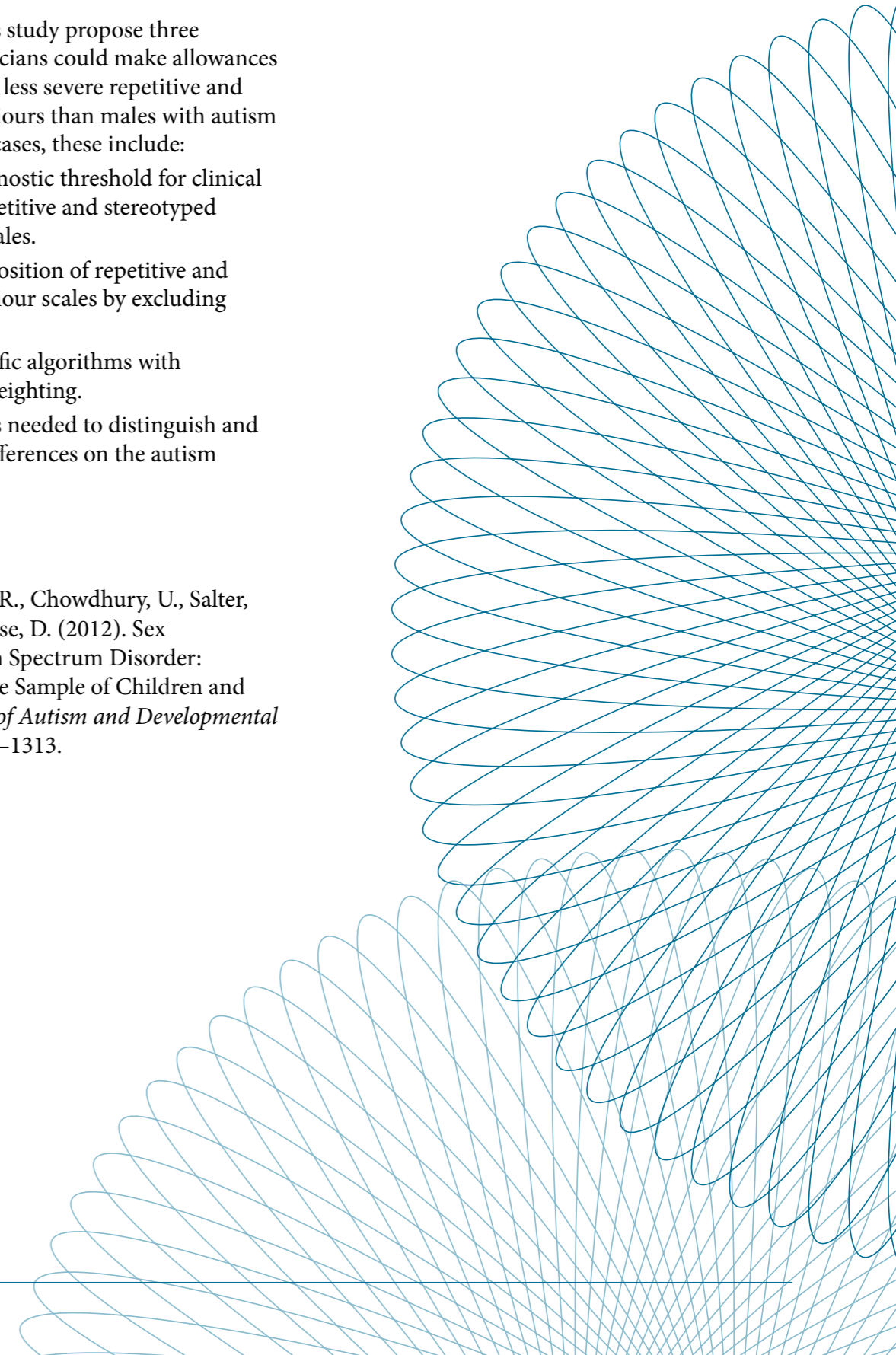
(by the authors)

- In this study teachers were less likely to report difficulties with emotional symptoms and mental wellbeing for females with autism compared to males. This may make females less likely to be identified as cases, or for diagnosis to be delayed, which may have negative repercussions on when they receive appropriately targeted health care, early interventions and educational resources.
- This study found that females with autism had a tendency to have less severe repetitive and stereotyped behaviours than males with autism, which may impact on females receiving a diagnosis of autism, as some clinicians will not consider an autistic diagnosis without the presence of repetitive and stereotyped behaviours.

- The authors of this study propose three possible ways clinicians could make allowances for females having less severe repetitive and stereotyped behaviours than males with autism when diagnosing cases, these include:
 - Lowering the diagnostic threshold for clinical significance of repetitive and stereotyped behaviours in females.
 - Altering the composition of repetitive and stereotyped behaviour scales by excluding sex-bias items.
 - Creating sex-specific algorithms with differential item weighting.
- Further research is needed to distinguish and understand sex differences on the autism spectrum.

Full Reference

Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A. and Skuse, D. (2012). Sex Differences in Autism Spectrum Disorder: Evidence from a Large Sample of Children and Adolescents. *Journal of Autism and Developmental Disorders*, 42, p. 1304–1313.



GENERALIZED EFFECTS OF SOCIAL STORIES WITH TASK ANALYSIS FOR TEACHING MENSTRUAL CARE TO THREE YOUNG GIRLS WITH AUTISM

BACKGROUND

The National Commission on Adolescent Sexual Health (1995) defines sexuality as 'the sexual knowledge, beliefs, attitudes, values, and behaviours of individuals' and recognises it as a normal and healthy part of life. While children typically discover their sexuality through casual social encounters, the need for appropriate sexual development education for young people with autism is well documented. Maturation and menstruation are critical development milestones for any young woman, including a young woman with autism. Despite this, the majority of research pertaining to menstrual care skills is specific to individuals with intellectual disabilities.

The goal of a Social Story is to share accurate social information that is easily understood by its audience. Social Stories have been used with individuals with disabilities and are an emerging intervention for individuals with autism.

RESEARCH AIMS

The purpose of this pilot study was to evaluate the effectiveness of a parent-implemented Social Story intervention with an embedded visual task analysis on how to change a sanitary pad and a checklist to teach menstrual knowledge to three young girls with autism.

RESEARCH METHODS

The research took place in Southern California and was supported by Grant H325K080108, Office of Special Education programs. The participants' parents were recruited from a Parent Group using the following criteria: (a) gender, (b) onset of menstruation had not yet occurred, (c) parents reported that menstrual self-care had not been taught, (d) parents viewed the acquisition of menstrual-hygiene skills as important and (e) female parent was willing to collect data and implement the intervention.

Three adolescent females with autism and their parents participated in this study.

- Haley was aged 12 at start of study. She attended public elementary school. According to her assessment teams, her reading comprehension reflected grade level 2. She was able to express her basic needs and answer who, what, where questions using words and phrases.
- Natalie was 11 years old at the start of study. She attended public elementary school. Her parents reported she read at 4th grade reading level and her receptive and expressive vocabularies were within typical limits for her age. She was able to maintain appropriate communication exchanges and respond to open-ended and yes/no questions.
- Susan was aged 9 years at the start of the research. She attended school for individuals with disabilities and according to her educational team reports she read at 2nd grade reading level and her receptive and expressive vocabulary skills were within typical limits for her age. Susan was able to respond to who/what/where and yes/no questions appropriately.

All three participants could independently follow a typical bathroom routine and received moderate or high scores in adaptive living skills on the Vineland Adaptive Behaviour Scales.

The intervention sessions and data collection were conducted by participants' mothers in each home. Only participants and their mothers were in the bathroom during observations due to Institutional Human Subject Review Requirements.

The authors created a Social Story on puberty and menstruation which was divided into three separate sections: Growing Up, My Period, and How to Take Care of My Period which included an explanation of the steps and behaviours included in the task analysis.

A task analysis for changing a sanitary pad comprising of 11 steps was also created.

The first author met with each mother to ensure the Social Story was clear and appropriate for the family's cultural values and preferences and additional information such as images or statements were added and they were individualised by adding the mother's and the participant's photograph. Prior to intervention, the first author met once with each parent to explain how to conduct the intervention, to answer parents' questions and to describe how to use the Social Story. To keep intervention procedures simple, the following format was agreed:

- (a) Parents read each page out loud and with enthusiasm to keep participants' interest.
- (b) Parents took turns in reading the Social Story as long as their daughter showed interest.
- (c) Parents asked the questions located at the bottom of each page and recorded the participant's answer on the given data sheet.
- (d) Parents provided the correct answer for incorrect responses and moved on to the next section.
- (e) Intervention; once per day at a time that suited the family routine.

The mothers were trained in their own homes on how to use and score the task analysis, how to score the data sheets, the importance of eliminating assistance and praise. Each step of the task analysis was modelled for the mothers to ensure their understanding and consistent replication of the intervention.

Baseline data was collected on each step of the task analysis using a multiple opportunity assessment procedure.

Data was collected during intervention using a questionnaire and data collection from the task analysis. During intervention it was identified that two of the girls omitted steps in the task analysis. To address this a simulation session involving red syrup being placed on a pad and the pad placed on the participant's underwear prior to direction, 'change your pad' was included. This focused on participants' learning to distinguish a clean pad from a dirty pad. Also during intervention general knowledge about maturation and puberty was added.

Findings were evaluated after intervention and one year post intervention.

ARTICLES REVIEWED

Despite the importance of sexual education for individuals with autism this area is under researched. Several sexual education curricula and guidelines have been designed and published. Two examples of these are the TEACCH program and the Devereux Foundation programme. The TEACCH curriculum is divided into four developmentally sequenced levels focusing on teaching appropriate behaviours and habits, teaching skills related to personal hygiene, and understanding sexual anatomy and functioning. Level four addresses a variety of social relationships and is designed for individuals with higher social functioning.

The Devereux Foundation curriculum involves parents in developing their children's skills and knowledge and includes body parts and functions, social/sexual behaviour, the sexual lifecycle, dating, marriage, parenting, establishing relationships, abuse awareness, boundary issues, assertiveness, and self-esteem.

The authors carried out a literature review on Social Stories and reported the following on two reviews:

- A review in 2005 by Nichols et al on ten studies found they were less effective when used with individuals with Asperger's Syndrome. Nichols et al expressed methodological concerns regarding these studies and suggested that Social Stories be used only with ongoing individual monitoring to evaluate effectiveness.
- Test et al (2010) carried out a meta-analysis on 28 studies published between 1995 and 2007. They found many of these studies had methodological issues which included but were not limited to research design, absence of social validity measures, and lack of maintenance and generalisation data to inform researchers about potential long-term effects.

The authors found that Social Stories have been used effectively with individuals with disabilities and their use with individuals with autism is emerging.

An omission identified in the Social Story literature reviewed by these authors was the lack of generalisation data to inform researchers about potential effects of the intervention across conditions or situations. The authors also found that research has neglected the area of teaching skills related to puberty and menstrual care for individuals with autism.

Existing research focuses primarily on masturbation and inappropriate behaviours associated with masturbation and is specific to individuals with intellectual disabilities and not young women with autism.

RESEARCH FINDINGS

Menstrual Care: Additional steps needed to be added to the task analysis. This resulted in all three girls being able to complete all the steps in the task analysis independently.

Menstrual Knowledge: The results of this study revealed all three participants were able to understand and answer the comprehension questions posed about the Social Story and to answer the knowledge questions regarding general maturation.

In the post-intervention questionnaire the authors reported that the overall parental rating was highly effective. The authors were only able to contact two sets of parents for the one year follow-up. They reported that the intervention was very helpful for preparing their daughters for menses. One parent reported that she no longer used the intervention as her daughter was able to independently perform menstrual care both at school and at home. This mother also reported her daughter did not have any fear when she first began menses. The other mother reported she did not use the intervention on a regular basis, but would once her daughter begins menses.

IMPLICATIONS FOR PRACTICE

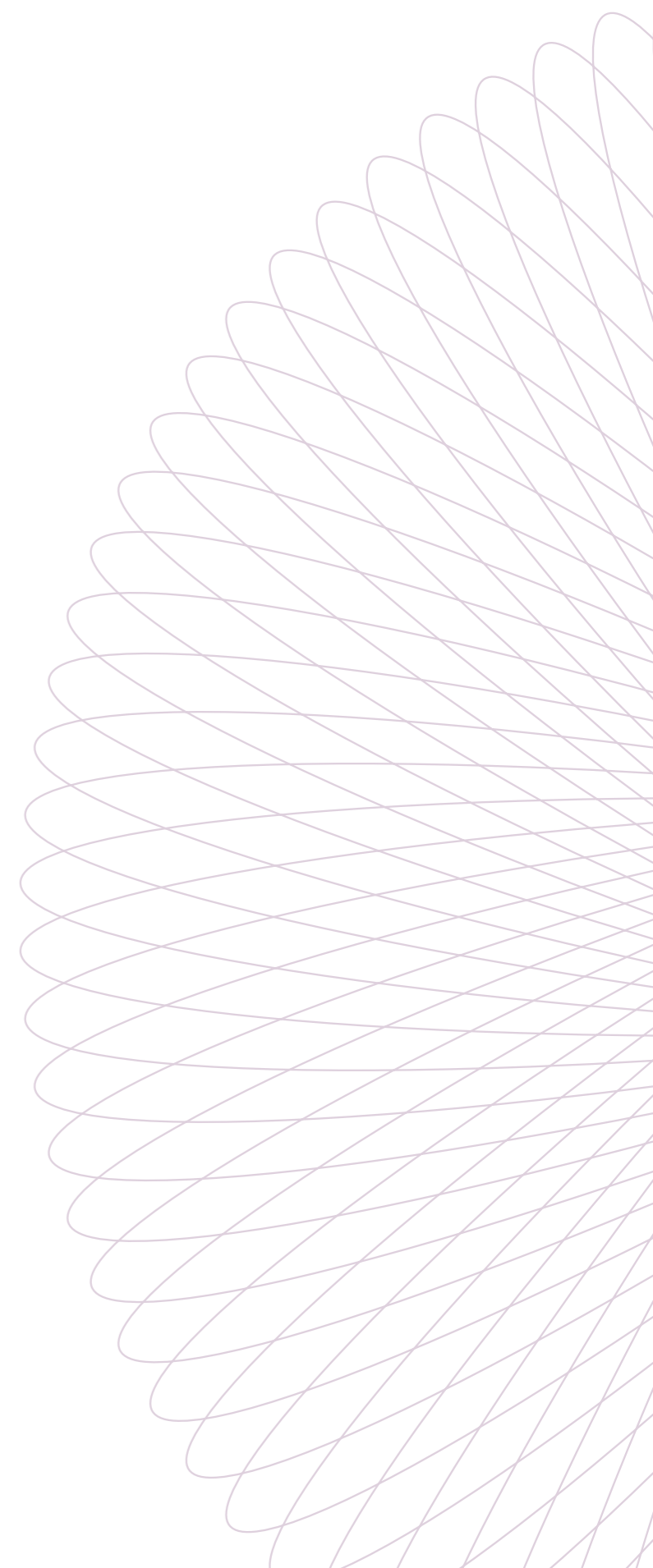
(by the authors)

- Research on the use of Social Stories as an intervention with individuals with autism is emerging and so far the outcomes are promising.
- The authors found that the use of this Social Story intervention which included visual supports and a task analysis was effective in increasing all three female participants' functional living skill of changing a sanitary pad.

- Parents found the inclusion of knowledge on maturation and menses effective.
- One of the participants began her first menses during the study and observations were conducted in vivo. The mother reported that her daughter did not have any fear during the first menses and that she continues to independently change her sanitary pad.
- At one year follow-up, the other mother reported that her daughter had started to ask meaningful and spontaneous questions about concepts related to menstruation.
- The findings of this small pilot study suggest that an intervention incorporating a Social Story, a task analysis and knowledge about menstrual care and maturation increased understanding of basic concepts about growing up and menstruation care for young women with autism.
- The outcomes of this pilot study were based on parent reports; it would be beneficial for educational professionals if future research could gather data from the practitioners in the school setting as well as the home setting.

Full Reference

Klett, L. S., Turan, Y. (2011). Generalized Effects of Social Stories with Task Analysis for Teaching Menstrual Care to Three Young Girls with Autism. *Sexuality and Disability*. 30(3), p.319–336.



BEING A GIRL IN A BOYS' WORLD: INVESTIGATING THE EXPERIENCES OF GIRLS WITH AUTISM SPECTRUM DISORDERS DURING ADOLESCENCE

BACKGROUND

The researchers claim that much of the work dealing with adolescence and autism has tended to focus on males and therefore see the results of this work as a means of going some way to highlighting the gap in both literature and research. They claim that the disparity in work emanates from the difficulty in detecting females in the early years; reasons for this include the hypothesis that girls have relatively strong skills in:

- Social interaction, including the ability for pretend play.
- Communication.
- Social imitation.
- Ability to focus.

Thus, girls appear to present fewer behavioural issues compared to boys with autism.

It is claimed that adolescence is difficult for everyone but the skills needed to fathom the complexities of girl-to-girl friendships makes it appear to be more difficult for girls with autism. Female adolescent relationships rely strongly on reciprocal sharing, emotional support, social problem solving, all requiring the ability for fast paced responses; simply put, teenage girls tend to 'talk' while boys tend to 'do'. This seems to cause great difficulty for girls with autism as they attempt to form, develop and maintain peer friendships and may have an adverse effect on their social and emotional development through this crucial stage of maturation.

RESEARCH AIM

The research, which is noted as being a preliminary investigation, aims to consider the experiences of adolescent girls with autism from their own perspective and that of their mothers through a range of domains including physical, emotional, social and sexual.

RESEARCH METHOD

The researchers chose an interpretative phenomenological analysis to their multiple-case study approach of in-depth, semi-structured interviews, allowing everyone to speak freely, openly and extensively about their experiences, with three mother-daughter dyads and two additional mothers. The girls with autism were all within the age band of 12 -17 years.

RESEARCH FINDINGS

Seven key areas of concern emerged from analysis.

1. Diagnostic issues

Each mother felt that principally attaining a diagnosis proved problematic as their daughter did not appear to meet the set criteria. The late diagnosis meant that their daughter did not receive early intervention and relevant support services.

2. Being surrounded by boys

Several mothers reported that whenever they received the support and their daughter was afforded a place in an educational setting particular for children with autism, the girl was invariably surrounded by boys and thus their daughter was not even 'fitting in' in this specialist facility. However, one mother pointed out that being surrounded by boys meant that her daughter did not have to engage and try to be included in girl-to-girl relationships, which can also prove difficult. The girl was then able to engage in interactions based on interests rather than gender specific friendships.

3. Experiences in high school

Varied responses, both positive and negative, were gathered in respect to high school.

Positives:

- Afforded greater opportunities with a broader range of subjects.
- A greater variety of students and experiences.
- A more structured environment.

Negatives:

- Class work was more difficult or simply not motivating, thus uninteresting.
- Challenges making friends.
- Managing this larger environment.
- The mothers raised the issues.
- Mainstream class teachers may not be adequately prepared for teaching girls with autism.
- Transitioning to high school as their daughters now had to deal with multiple teachers rather than the single teacher in the autism specific previous classroom.

4. Complexity of adolescent female relationships

One of the girls said that she had difficulty forming friendships and relationships with her female peers as she felt that they ignored her, bullied her or picked on her simply because she was different. However, other girls did not read these social cues, due to a different processing time thus not fully following a conversation or interaction, and although the mother thought the daughter was being excluded, the girls did not appear to be aware of their exclusion.

The mothers agreed that their daughters had difficulty with friendships because female teenage relationships can be complex and their daughters did not have a shared interest in topics such as fashion, hair grooming and hair styles, thus having a negative impact on their ability to form and maintain lasting relationships.

The girls said that they preferred the company of boys with autism as they were shared interest based friendships rather than relying on a perceived 'girl' interest.

5. Puberty and its related issues

Although the mothers were concerned about the onset and management of menstruation, they were surprised at how well their daughters dealt with the situation in a factual and logical manner, whenever it was explained and discussed in a developmentally appropriate manner. However, this also led to their daughters being open to everyone about their body changes and menstruation, not fully grasping the concept that discretion is needed around what is socially seen as a private matter.

Hygiene routines, using deodorant, daily showering, were noted as being a challenge for the mothers and subsequently their daughters.

6. Sexual relationships and concerns

Three out of the five mothers felt that their daughters were not fully exposed to sexual issues and romantic relationships as they showed limited interest in boys, and had a willingness to talk to their parents about all issues.

However, it was noted that the girls faced specific challenges including becoming fixated on particular issues, misunderstanding with personal boundaries, innately appreciating and expressing their own sexuality and being confused in respect to 'typical teenage behaviour' such as flirting. All of the mothers expressed concerns that their daughters may be vulnerable and therefore more likely to be sexually exploited that their typically developing peers as they may misconstrue and act inappropriately in social situations thereby being open to others taking advantage of them.

7. Impact of having an adolescent daughter with autism

Each of the mothers thought that having a daughter with autism meant that they were too involved in many aspects of their daughters' lives, connection with school, helping with homework, facilitating hygiene routines, planning activities, actions that their friends of typically developing girls has relinquished. Although the mothers enjoyed having such close relationships with their daughters, they also worried about the future, their daughter having friends and being accepted by others, having an array of career and social opportunities and achieving personal growth, saying that to cope with this stress they relied heavily on other mothers of daughters with autism, which at times can be a superb release, yet, it can also be isolating.

IMPLICATIONS FOR PRACTICE

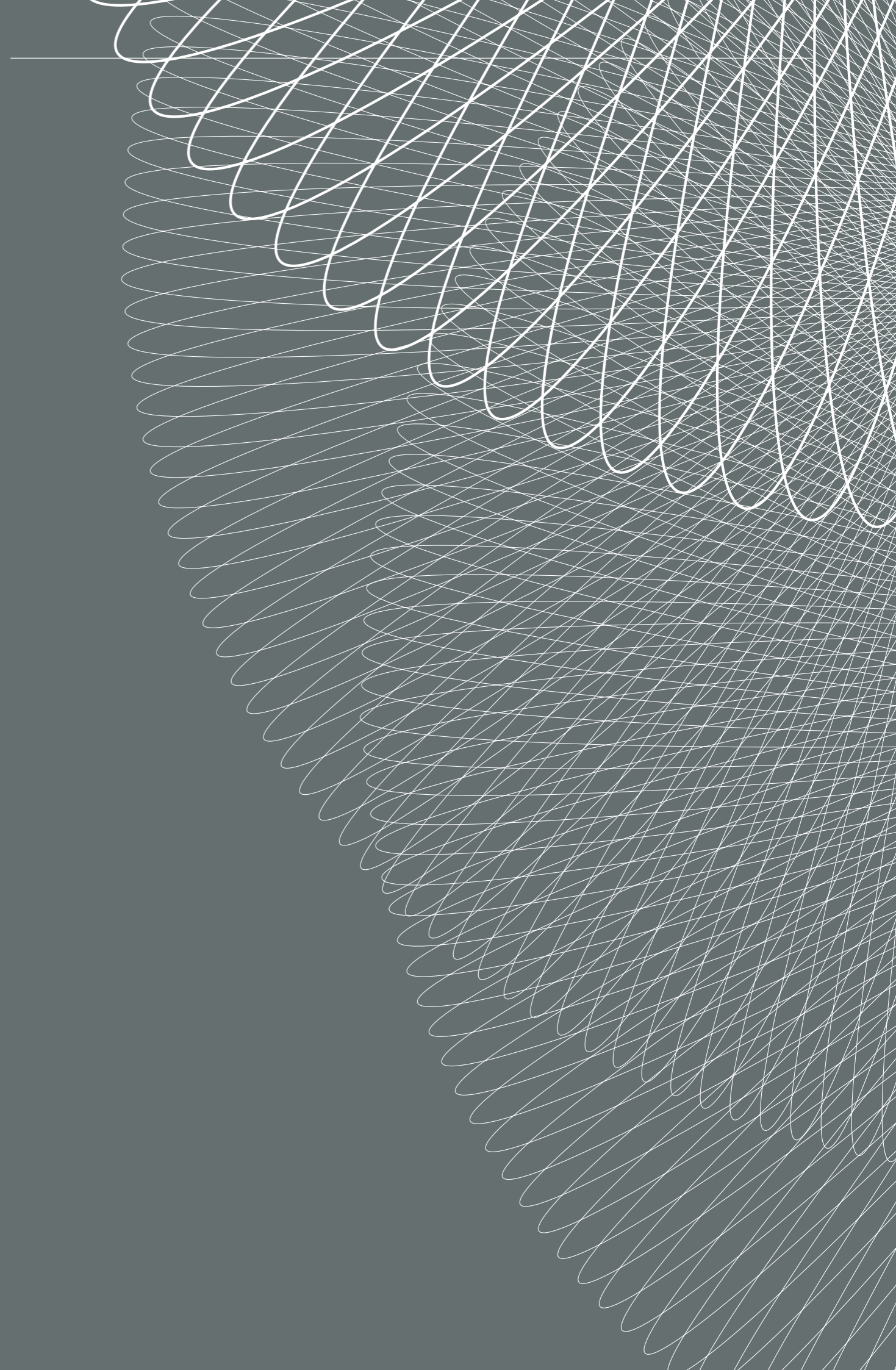
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- All involved in the care and education of children must be aware of the differences in the presentation of autism in girls from the more commonly recognised traits displayed by males. This may mean that girls are diagnosed earlier and afforded early intervention and autism specific strategies.
- Girls with autism may experience difficulty being included by their peer group and this isolation may lead to mental health problems, depression and anxiety accruing from social isolation. Therefore, girls may need in-depth support to achieve appropriate and socially acceptable communication and social skills, strategies to develop individual self-esteem and self-identity.

- The peer group need support and education to understand and accept difference and increase tolerance of others.
- Sexual education, as a home/school/health service collaboration, cannot be confined to teenage years. The individualised developmentally appropriate process must begin in the early years covering issues such as personal boundaries, the physical changes to expect through development but in particular during puberty and acceptable ways of expressing sexuality.
- Greater opportunities for social interaction for all family members must be explored and consideration given to the provision of gender specific groups as an option for the girls with autism and their parents as in such an environment they can all feel accepted and not have to explain anything to others.

Full Reference

Cridland, E. K., Jones, S. C., Caputi, P. and Magee, C. A. (2014). Being a Girl in a Boys' World: Investigating the Experiences of Girls with Autism Spectrum Disorders during Adolescence. *Journal of Autism and Developmental Disorders*, 44, p. 988-1000.



CONCLUSION

The articles summarised address a range of relevant areas within the issue of autism and girls. These range from gender differences before, during and after diagnosis as well as social, emotional and self-care issues. There is a growing body of literature both empirical and anecdotal indicating that autism in girls presents differently and that girls with autism face differing difficulties to their male counterparts. These differences can include:

- Differing experiences with diagnosis; in some instances the diagnostic process for girls can be longer or delayed compared to boys.
- Differing profiles of behaviours, strengths and impairments with some girls having stronger social and imitation skills than boys.
- Research in this Bulletin also indicates that the relationship with and presentation of any special interest can be different.
- Girls and their peers may need additional support and education in understanding autism in friendship skills and support with social skills and self-care skills.

For those engaged in autism research there is a need to understand the potential differences in presentation, particularly in relation to repetitive behaviours. There is a need generally for more girls and women to be involved in autism research.

YOUR OPINION

The Centre trusts that you have found this Research Bulletin informative. It would be appreciated if you would take a few minutes to provide the Centre with feedback in relation to this bulletin by clicking on the survey link below.

Survey for Autism and Girls (Volume 2)





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