

# Puberty: challenges for adolescents on the autism spectrum

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## Abstract

Puberty can be a difficult time for many children and can present even more problems for children who have an autism diagnosis with additional social communication difficulties, restricted patterns of behaviour, sensory differences and elevated levels of anxiety. The majority of the literature on this subject examines the effects of puberty on adolescents with autism; there is a scarcity of literature on the relationship between autism and the timing of puberty.

This article discusses findings from the literature and identifies commonalities with typically developing children, as well as differences. Issues faced by girls on the autism spectrum who are experiencing puberty are also explored. Particular focus is given to the problematic sexual behaviour of adolescents on the autism spectrum and strategies to overcome this including education programmes covering sexual awareness, social skills training with healthcare professionals offering support to families.

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## Introduction

Autism spectrum disorder (ASD) is a lifelong neurological condition (Happé 1998, Murray 2012), typified by social communication and interaction impairments with restrictive and repetitive patterns of behaviour (Volkmar and Pauls 2003, Leekam et al 2011, American Psychiatric Association 2013). Common features of ASD also include unusual sensory processing (Crane et al 2009, Matsushima and Kato 2013), elevated levels of anxiety (Gillott and Standen 2007, Trembath et al 2012) and frequent patterns of concerning behaviour (Hattier et al 2011, Hill et al 2014).

There has been a substantial increase in the number of people diagnosed with an ASD. Gillberg and Wing (1999) stated that in the late 1970s the autism prevalence ratio in some European countries was 1 in every 2,500 young people (0.04%), however, more recently the average worldwide prevalence of autism has been reported as

about 0.7% of the population (Lai et al 2014), with childhood autism in the US rising to 1 in 68 (1.47%) (Baio et al 2018).

Although it is commonly thought that autism is more prevalent in males with male-female gender ratios identified as 4.5:1 and 2:1 (Werling and Geschwind 2013, Ferri et al 2018), an increased awareness of the difficulties of diagnosing women and girls (Dworzynski et al 2012), as well as recommendations for changes to the diagnostic and intervention process (Rivet and Matson 2011, Satchell 2016), should see an elevation in diagnosis among women and girls.

Puberty is commonly reported as a difficult time for people on the autism spectrum (Cridland et al 2014, Bagatell 2016, Mademtzi et al 2018). Puberty is the developmental stage of life when a child matures into an adult and becomes capable of sexual reproduction (Robeva and Kumanov 2016), undergoing a wide

range of transitional changes which can be physical, emotional or cognitive (Keulers et al 2010, Ellison and Reiches 2012, Palmer and Williams 2013, Reena 2015).

Relationships with peers during puberty become more important and complex, often leading to depression and anxiety if they fail (Laugeson et al 2012). Studies have shown puberty to be a difficult time for typically developing (neurotypical) young people (Angold and Costello 2006, Mundy et al 2015), however, puberty has been shown to result in a wider range of problems for those with an autism diagnosis (Cridland et al 2014, Bagatell 2016).

### Pubertal timing

Puberty is now thought to encapsulate the two distinct biological processes of adrenarche and gonadarche (Robeva and Kumanov 2016, Byrne et al 2017), although earlier literature has defined puberty as an ongoing developmental continuum, preceded by the separate adrenarche process (Institute of Medicine and National Research Council 1999).

Adrenarche can begin as early as six years of age (Rege and Rainey 2012). The process initiates when the adrenal gland matures, producing androgens such as testosterone (Robeva and Kumanov 2016, Oberfield et al 2018). This androgen production results in the growth of pubic and axillary hair, increased oil production and changes in body odour (Rege and Rainey 2012).

Gonadarche happens independently of adrenarche, as well as slightly later (Ambler 2013), and occurs when the hypothalamus matures, activating the pituitary gland and resulting in a release of hormones into the bloodstream (Robeva and Kumanov 2016). This hormonal release then stimulates development of the male and female gonads, testicles and ovaries, resulting in sperm production or ovulation (Ambler 2013).

There is a scarcity of literature which explores the effect of an ASD on the timing of puberty; a search of the databases Medline, CINAHL, and Academic Search Premier using the terms: autism/timing/

time and puber\* returned only one study of relevance – May et al (2017) which was a secondary data analysis of a large national cohort ( $n=3,454$ ) showing there was no difference in pubertal timings when comparing the 94 participants with ASD against the larger control group. Further ancestry and library searches reveal limited studies on the subject, although the lack of disparity between the physical maturation of adolescents on the autism spectrum and control participants has been reported elsewhere (Gabriels and Van Bourgondien 2007). However, other research on pubertal timing presents conflicting results. Eriksen (2016) explored the experience of 32 girls on the autism spectrum, using the menses as the marker for the beginning of puberty and found that, for participants who also had a sibling on the autism spectrum, the average age at menses (AAM) was significantly earlier at 11 years than neurotypical participants who had no family history of ASD – nearly 13 years.

A study by Whitehouse et al (2011) reported that early strong signs of autism in two year olds resulted in later AAM than those who did not display autistic traits, or those who only displayed mild indicators. It should be noted that there are a range of other factors documented in the literature that have been associated with pubertal timing in the general population: nutritional balance (Soliman et al 2014), lack of a male parental presence (Tither and Ellis 2008), and obesity (Kaplowitz 2008), showing that variance in pubertal timing may not be attributed to ASD alone.

### Effects of puberty

There is a dearth of knowledge on the relationship between autism and pubertal timing; the majority of literature examines the effects of puberty on adolescents with autism. Bagatell (2016) used a thematic analysis methodology to explore the dynamics of five families with adolescents on the autism spectrum. The study identified three themes: the essential need for routine; the shifting of routines with the onset of

### Key points

- Puberty presents a wider range of problems for adolescents on the autism spectrum
- There is a shortage of literature exploring the effect of having an autism spectrum disorder on the timing of puberty
- Adolescents with autism should have access to specific social skills training and education programmes that include content on sexual awareness
- Healthcare professionals need to offer families of adolescents with autism additional support on how to communicate about sexual development to their child

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puberty, commonly linked to behavioural concerns; and accommodations that are made to avoid challenging incidents.

Neumeyer et al (2013) found that peripubertal boys on the autism spectrum showed lower bone mineral density than controls. However, this finding was not thought to be directly due to the effects of puberty itself, but more from a deficiency of vitamin D, resulting from decreased lactose intake and sunlight exposure in the autism group due to their social inhibition. Gillberg and Schaumann (1981) highlighted five case studies of deterioration in behaviour and learning during puberty and Mayes et al (2012) also reported a high prevalence of behavioural difficulties in their study group ( $n=1609$ ) containing 435 young people with autism aged between 6-16 years.

It is not documented, however, whether these behavioural difficulties were present before or after puberty, so it is not possible to identify whether or not these patterns of behaviour were related to the process of puberty. Behavioural difficulties, problems with social adjustment and increased risk of mental health problems are not unique to people with autism, but are also reported in neurotypical adolescents experiencing puberty (Graber 2013, Mensah et al 2013, Thompson 2017).

**The female experience**

Many studies have predominantly used male samples or mixed sex samples, possibly due to the higher diagnosis rate in boys (Werling and Geschwind 2013, Ferri et al 2018). In answer to these studies, Cridland et al (2014) used a series of semi-structured interviews to examine the experiences of girls on the autism spectrum. They found a number of similar problems to boys on the autism spectrum:

- » A late diagnosis.
- » Transition into and coping with high school.
- » The challenges of an increased need for personal hygiene.
- » Understanding and developing personal boundaries.

In particular to adolescent girls with autism, Cridland et al (2014) also found other issues such as concerns over the onset of menstruation and its ongoing management, sexual vulnerability and the difficulties of socialising with neurotypical girls.

Typically developing adolescents display different methods of dealing with conflict than those with autism; neurotypical boys tend to solve issues using physical aggression, whereas girls will practise indirect or relational aggression, often by the use of a third party to create rumours, gossip or group exclusion (Card et al 2008, Nichols et al 2009). This type of conflict is not always readily identified by girls on the autism spectrum and can frequently lead to increased social isolation, eating disorders, depression, poor self-image and anxiety compared with neurotypical girls or boys with autism (Rivet and Matson 2011, Cottenceau et al 2012, Mandy et al 2012, Solomon et al 2012).

Mademtzi et al (2018) used a thematic analysis following a series of focus groups to explore the experience of parenting adolescent girls on the autism spectrum and discovered similar themes to those reported by Cridland et al (2014), which also reinforces earlier work by Navot et al (2017) examining the parental experience. In a more specific study of experiences of menstruation, Eriksen (2016) found differences to neurotypical girls where participants with autism were less likely to report premenstrual symptoms than neurotypical girls, although they reported menstrual, physical, behavioural and emotional symptoms at similar rates. The girls on the autism spectrum who reported menstrual symptoms also indicated greater behavioural and emotional symptoms than neurotypical girls.

**Problematic sexual behaviour**

The onset of puberty in adolescents on the autism spectrum can often lead to hypersexuality or other problematic sexual behaviours (Hellemans et al 2007, Dekker et al 2015). In a review of the literature on normative sexual behaviour in

typical adolescents, Tolman and McClelland (2011) identified three domains:

- » Sexual behaviour – solitary or with others.
- » Sexual selfhood – knowledge, identity and beliefs.
- » Sexual socialisation – how the adolescent learns about sex from different people.

These paradigms were later used by Dewinter et al (2013) in their review of 55 studies on the sexual development of young people with autism. They found a range of sexualised behaviour such as masturbation, reported to be at lower rates than neurotypical adolescents, as well as public or compulsive masturbation, and with lesser frequency arousal by unusual objects or an interest in young children. Dekker et al (2017) tested these domains: differences were stated by self-reported means and parental reports in the sexual socialisation and sexual selfhood domains, with differences in the sexual functioning domain reported only by parents.

In an earlier longitudinal study Dekker et al (2015) identified that autistic traits, specifically those of limited social interest and social regulation, gave a higher risk of psychosexual behaviours. Helleman et al (2007) interviewed the caregivers of 24 male adolescents on the autism spectrum and reported that most of them had displayed some sexual behaviour, 29% of this was described as being deviant and included unwanted sexual touching, inappropriate masturbation and unwanted attempts at intercourse. This also supports the previous work of Ruble and Dalrymple (1993), who studied the social and sexual awareness of 100 adolescents with autism via a family member questionnaire, and found that a variety of behaviours were present which were deemed as inappropriate by parents: touching their genitalia when in the community (65%), public masturbation (23%), inappropriate touching of the opposite sex (18%) and using an unusual object for masturbation (14%).

A study of 184 adolescents and young adults on the autism spectrum, which

examined paraphilia and inappropriate sexualised behaviours, found that there was a significant connection between paraphilia and autism severity, intellectual impairment or adaptive functioning, showing that a quarter of the participants displayed paraphilic sexual practices (Fernandes et al 2016).

In contrast to these studies, evidence has also been found showing little difference between the sexual practices of adolescents with autism when compared with typical adolescents. In their study comparing 50 young people on the autism spectrum against a control group of 90 neurotypical adolescents, Dewinter et al (2015) found that sexual behaviour of the ASD group was similar to the neurotypical controls. The only difference being that the participants with autism seemed more tolerant of homosexuality than the control group – 76% versus 38% respectively; this may be reflective of the reported prevalence of gender dysphoria and homosexuality which has been shown to be significantly higher in people on the autism spectrum (George and Stokes 2017).

Allely and Creaby-Attwood (2016) found that there was no evidence to support a higher prevalence of sexual offence in the autism population following their systematic review of the literature on autism, sexual offences and the criminal justice system. However, many of the case studies examined did indicate a naivety and openness among participants with autism when discussing often deviant sexual behaviour, as well as the lack of understanding of the effect of their behaviours on others and an immediate confession when confronted with their actions.

Sexualised behaviour can often be explained in people with autism by their lack of social awareness and inhibited understanding of where normal boundaries lie (Fourie et al 2017). Griffiths et al (2013) revisited the theory of counterfeit deviance. This is used in clinical assessment to identify a sub-group of individuals with intellectual disability, whose apparent paraphilic behaviours serve a different function than the

fulfilment of sexual fantasies or urges. They offered 11 different hypotheses about why problematic sexual behaviour may occur in people with learning disabilities including:

- » Living in sexually restrictive environments.
- » Inappropriate modelling of other people's behaviours.
- » Lack of courtship skills or sexual knowledge.
- » Chronic sexual arousal due to medication side effects or environmental conditions.
- » Lack of opportunity to develop relationships or social skills.

While counterfeit deviance hypothesises that deviant sexual arousal can happen with good sexual knowledge, it also acknowledges that a sexual offence could occur due to poor sexual knowledge; it is not, however, offered as an explanation for all sexually offending behaviour among people with learning disabilities.

### Supportive strategies

The literature suggests that patterns of problematic sexual behaviour in adolescents on the autism spectrum can be minimised by the use of medication. Deepmala and Agrawal (2014) reported on the effective pharmacological treatment of a 13-year-old boy whose hypersexual patterns of behaviour began at puberty and were causing significant distress to his family and care staff.

Taking propranolol resulted in significant improvements in his sexual behaviour, which remained stable for a year. Fosdick and Mohiuddin (2016) document the cessation of aggressive sexual behaviours in a 15-year-old boy on the autism spectrum using leuprolide acetate. Medication can, however, frequently bring additional problems such as unwanted side effects (Joint Formulary Committee 2013) and it therefore seems that a more appropriate and ethical approach to avoid possible counterfeit deviancy, or to support problematic patterns of behaviour in adolescents on the autism spectrum, would be to increase their social skills and sexual knowledge (Curtis 2017, Fourie et al 2017).

Hannah and Stagg (2016) found that standard sex and relationship education is not sufficient for adolescents on the autism spectrum. Following their examination of sexuality of 23 male ( $n=17$ ) and female ( $n=6$ ) adolescents with high-functioning autism, Stokes and Kaur (2005) suggest that adolescents on the autism spectrum may benefit greatly from sexual education, if embedded into a larger social skills programme.

Visser et al (2017) used a randomised controlled trial to examine the effects of a training programme for psychosexual awareness in adolescents with autism. They found that, while there was a reported increase in psychosexual awareness and parent-reported social functioning, the training programme did not result in an increase in romantic skills or decrease in inappropriate sexualised behaviour. However, across the duration of the study, there was a generalised improvement in psychosexual functioning in most of the adolescents whether they received the training or not, indicating that the sexual knowledge and behaviour of adolescents with autism may improve over time regardless of any intervention.

Adolescents on the autism spectrum may not have access to specific social skills or psychosexual training and they may not be receiving appropriate sexual education from their parents or school. Their sexual learning, therefore, may either be self-taught, through making mistakes, or come from other less appropriate sources such as television, the internet or pornography (Mehzabin and Stokes 2011, Brown-Lavoie et al 2014). Ballan (2012) found that parents had difficulties in communicating sexual content to their children, which leads to them being sexually vulnerable or participating in sexually risky patterns of behaviour. Murphy and Young (2005) concluded that people were twice as likely to be sexually abused if they had a developmental disability. Holmes and Himle (2014) reported a connection between the parents' expectation of their child's sexual activity



and the depth and extent of the sexual education the parents delivered, linked to the child's IQ and developmental level.

## Discussion

It is clear from the literature on autism and puberty that adolescents with autism display many commonalities to neurotypical adolescents, but they also display many differences. The characteristic autistic resistance to change results in increased difficulty with alterations and additions to personal care routines, particularly during menstruation.

Changing social rules, which become progressively more subtle and complex, may leave adolescents with autism socially isolated or experiencing mental health problems or depression. Hormonal changes and their respective effects on physical sexual maturity and psychological sexual awakening mean that puberty needs to be a period of concrete and unemotional guidance and education from capable people such as parents or teachers.

Due to lower parental expectations and understanding of the needs of the adolescent with autism as a sexual being, this education is frequently sparse or gained from inappropriate sources.

Alongside their inherent difficulty with understanding social rules and generalising skills, a person with autism is at high risk of sexual offence either as the perpetrator or the person offended against. To mitigate against this greater sexual vulnerability, the author recommends that adolescents with autism should have access to specific autism-related social skills training and education programmes, with content related to sexual awareness. Families of adolescents on the autism spectrum should also be given additional support from appropriate health professionals on ways to communicate social and sexual skills to their child.

## Conclusion

Further research is needed to address problematic sexual behaviour displayed by adolescents with autism and to mitigate the potential negative consequences. Healthcare professionals require a greater understanding of the root causes of problematic sexual behaviour in adolescents with autism and the social and environmental modifications required to minimise them. Adolescents on the autism spectrum need to be supported by their family and healthcare professionals to attain healthy and functioning sexual experiences.

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