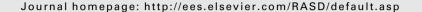


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Research in Autism Spectrum Disorders





Teachers' perspectives of the sexuality of children with autism spectrum disorders

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ABSTRACT

Individuals with autism spectrum disorders (ASD) experience sexuality issues, but there are very few studies looking at sexuality and autism. The present study aims to examine teachers' perceptions of sexual behaviors of 56 children with low functioning autism (LFA) and 20 children with high functioning autism (HFA) or Asperger Syndrome (AS). Teachers perceived children with LFA as exhibiting less socially acceptable behaviors, as possessing lessened awareness of privacy related rules, and as having more limited knowledge of typical sexual responses and behaviors in comparison to children with HFA or AS. However, teachers expressed more concerns for children with HFA or AS. These findings should be taken into consideration when designing intervention programs targeting sexuality of individuals with ASD.

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Sexuality and autism is a topic that has not been studied widely, as pointed out by Gabriels and van Bourgondien (2007) and Realmuto and Ruble (1999), but this does not mean that individuals with autism do not experience sexuality issues. The limited studies that have been conducted so far with interviews of individuals with autism or reports from their caregivers provide evidence that the former do show awareness of and interest in sexuality issues, which is manifested often through sexual behaviors (Harocopos & Pedersen, 1992; Konstantareas & Lunsky, 1997; Ousley & Mesibov, 1991; Van Bourgondien, Reichle, & Palmer, 1997). So, although individuals with developmental delay and autism spectrum disorders (ASD) have often been regarded as sexually immature (e.g., Ludlow, 1991) or asexual (e.g., Zigler & Hodapp, 1986), some individuals with high functioning autism or Asperger Syndrome have expressed interest in getting married or having intimate and sexual relationships (Newport & Newport, 2002).

Individuals with ASD enter the physical process of puberty roughly at the same time as their typically developing peers (Murphy & Elias, 2006), although due to the core deficits of ASD they continue to experience problems in cognitive and psychosocial functions. Gillberg and Coleman (1992) pointed out that the sexual drive is not usually accompanied by social maturity and this might lead to embarrassing situations. For example, Ruble and Darlymple (1993) reported that parents of children with autism described them as engaging in inappropriate sexual behaviors.

The lack of social understanding displayed by individuals with autism (Gillberg, 1984) can interfere with their ability to use their social judgment to assess whether they should perform certain behaviors in public or private places, how and why they should practice personal hygiene, and how to protect themselves from social exploitation (Gabriels & van Bourgondien, 2007). The use of echolalia (Tager-Flusberg, Paul, & Lord, 2005) can result in repetition of sexuality terms that individuals with autism have heard previously in inappropriate social contexts, resulting in embarrassment for the caregivers or misunderstanding by others (Gabriels & van Bourgondien, 2007). The tendency of individuals with autism to engage in repetitive, restricted, and

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stereotyped behaviors (APA, 1994) can aggravate their tendency to perform self-stimulating activities, such as masturbation, to an extent that can become problematic for any social exchanges. De Myer, 1979, Ruble and Darlymple (1993), and van Son-Schoones and Bilsen (1995) reported that parents of children with autism express their pressing worries about the sexuality of their children. However, researchers and professionals often hear from parents of individuals with autism that they have enough problems to deal with and sexuality should not be added to them (Henault, 2005).

There are many sexuality issues, such as masturbation or menstruation, which can pose as serious health and safety risks if they are not acknowledged and addressed. The complexities involved in sexuality, coupled with the sexuality behaviors and interests of individuals with autism, as well as the deficits that they experience in understanding social expectations can render them sexual victims or victimizers. Therefore, it is imperative to educate both caregivers and professionals working with individuals with autism how to better understand and address their sexual needs (Gabriels & van Bourgondien, 2007); ignoring them is not the answer.

Hellemans, Colson, Verbraeken, Vermeiren, and Deboutte (2007) recognize that the sexual development and behavior of individuals with ASD are largely neglected by research and state that many clinicians are asked to give advice to individuals with HFA or AS who are concerned about their sexuality. Gabriels and van Bourgondien (2007, p. 59) stress that "it is imperative that professionals working with school-age children and adolescents with autism to be alert to sexuality issues in this population so preparations to address and teach appropriate social boundaries and personal self-care can be made long before the child with autism enters puberty". It should also be stressed that the move towards the inclusion of individuals with ASD in educational and community settings has rendered the need to explore their sexuality even more pressing (Koller, 2000).

In order to design effective intervention programs for individuals with ASD, it is imperative to identify the behaviors that are problematic and do not conform to typical adolescent behaviors (Stokes & Kaur, 2005). However, since individuals with ASD may lack insight into their problematic behaviors (Attwood, 1998; Volkmar, 1987), most researchers have asked parents and caregivers about the sexual behavior of their children with ASD (e.g., Ruble & Darlymple, 1993; Stokes, Newton, & Kaur, 2007), while sexual knowledge was investigated in other studies (e.g., Edmonson, McCombs, & Wish, 1979; Penny & Chataway, 1982). Van Bourgondien et al. (1997) have argued that there is limited information on both the nature and the frequency of sexual behaviors of individuals with autism and that the level of autism, the level of mental retardation and the presence of verbal language are highly related to the nature of sexual behaviors. Most of theses studies have explored the sexuality of high functioning adolescents and young adults (e.g., Hellemans et al., 2007; Ruble & Darlymple, 1993; Stokes et al., 2007), despite the fact that 70% of individuals with ASD have an IQ of less than 70 (Ghazziudin, Ghazziudin, & Groden, 2002). In this context, the aim of the present study was to examine the sexual behaviors of children with ASD as reported by their teachers and to explore whether they are differentiated according to their level of autism.

1. Methods

1.1. Participants

The sample consisted of teachers of 76 children diagnosed with ASD. All the teachers were teaching in special schools or inclusion classes in mainland Northern Greece and were working with the child with ASD that they were asked to comment on for at least 8 months. There were 39 women and 17 men whose age ranged from 26 to 52 years old (mean age = 38 years and 8 months) and their teaching experience varied from 1 to 17 years (mean teaching experience = 9 years and 10 months). They all had a teaching degree and some kind of specialization in special needs educations in the form of training or postgraduate degree.

The 54 boys and 22 girls who were diagnosed with ASD were aged between 7 and 14 years old (mean age = 10 years and 7 months). There were 56 (73.7%) children with low functioning autism (LFA) with mean age of diagnosis 3 years and 7 months and 20 (26.3%) children with high functioning autism (HFA) or Asperger Syndrome (AS) with mean age of diagnosis 4 years and 5 months. There were 38 boys and 18 girls in the LFA group with mean age of 10 years and 4 months and 16 boys and 4 girls in the HFA or AS group with mean age of 10 years and 10 months. There was comorbidity in 23 out of the 76 participants (e.g., mental retardation, attention deficit disorder/hyperactivity, learning disabilities). The children were diagnosed with ASD from the Local Educational Authorities from a multidisciplinary team comprising of a psychologist, a psychiatrist, a speech therapist, and a social worker. The diagnosis of ASD was consistent with the criteria set by the DSM-IV (APA, 2000) – the participants met the criteria for autism and had no history of cognitive or language delay. The children with LFA had an IQ below 70, while the children in the HFA or AS group had normal IQ. Initial analysis showed that age and gender of the child did not have an effect on teachers' perceptions about their sexuality, so it was excluded from further analyses.

1.2. Measures

The questionnaire that was used for this study was developed by Stokes and Kaur (2005) and is called Sexual Behavior Scale (SBS). It was based on findings from studies carried out by Harocopos and Pedersen (1992) and Ruble and Darlymple (1993) and it was designed to measure parental perceptions about the sexual behavior of their children with ASD; in the present study, the questionnaire was modified to measure teachers' perceptions. Therefore, the words "the child with ASD" replaced the words "your child" of the original version of the SBS. The questionnaire measures five different aspects of sexual behavior: (a) social behavior: it includes seven items related to social companions and activities that are rated on a scale from

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