

Diversity in Ontario's Youth and Adults with Autism Spectrum Disorders: Increasing Social Involvement

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By: Barbara Muskat, PhD, RSW & Jason Manett, M.A., Ph.D. (Cand.), The Redpath Centre



Social involvement and friendships are important contributors to quality of life. Individuals with friends enjoy greater psychological well-being and have a greater sense of self-worth (Bagwell, Bender, Andreassi, Montarello, & Muller, 2005; Bukowski, Motzoi, & Meyer, 2009; Gupta & Korte, 1994; Voss, Markiewicz, & Doyle, 1999). Conversely, individuals who lack peer relationships experience loneliness, boredom, lower self-esteem, and negative mental health outcomes including depression and anxiety (Bagwell et. al., 2005; Carbery & Buhrmester, 1998; Orth, Robins, & Roberts, 2008; Whitehouse, Durkin, Jaquet, & Ziatas, 2009).

Struggles with social interaction are among the diagnostic criteria for Autism Spectrum Disorder (ASD) (APA, 2000). While these difficulties are commonly first observed in childhood, they may become embedded and more complex as individuals with ASD enter adolescence and adulthood. During this period, individuals with ASD may become increasingly aware of their social and behavioural differences, more motivated to engage in relationships, and develop more sophisticated understandings of friendship (Kanner, Rodriguez, & Ashenden, 1972; Szatmari, Brenner, & Nagy, 1989). Nevertheless, adolescents and adults with ASD continue to have few social opportunities and friendships (Barnhill, 2007; Engstrom, Ekstrom, & Emilsson, 2003; Jennes-Coussens, Magill-Evans, & Koning, 2006).

Individuals with and without ASD demonstrate similarities in the meaning they assign to long-term friendships (Bauminger et. al., 2008; Locke, Ishijima, Kasari, & London, 2010). Consequently, those with ASD are significantly affected by feelings of loneliness and isolation when they

fail to form them (Frith, 2004; Howard, Cohn, & Orsmond, 2006; Locke et. al., 2010; Tantam, 1991). Therefore, addressing the poverty of social opportunities and experiences among adults with ASD is critical from both a quality of life and a health perspective.

Very little is known about social interaction trends among youth and adults with ASD. An early study of peer relationships and participation in social and recreational activities by adolescents and adults with autism who live at home found that the likelihood of having friendships, peer relationships, and participating in social and recreational activities was low (Orsmond, Wyngaarden Krauss, & Malik Seltzer, 2004). A more recent study (Liptak, Kennedy, & Dosa, 2011) found that many youth had not gotten together with friends in the previous year, nor had they talked on the phone with a friend. The study concluded that numerous adolescents and young adults with autism become increasingly isolated over time.

Qualitative research examining the experiences of youth and young adults with ASD about their experiences with social relationships and friendship also reveals responses ranging from retreating from friendships to feeling ambivalence about friendship to pursuing friendships (Marks, Schrader, Longaker, & Levine, 2000). Others, interested in socialization, have described using a technique of "masquerading" (Carrington, Templeton & Papinczak, 2003), to mask/hide social difficulties in an attempt to conform and fit into their high school social scene.

Studies with adults with ASD found similarly divergent points of view (Jones, Zahl & Huws, 2001). Internet sites of adults with ASD reveal

that participating individuals expressed a sense of alienation from society, frustration with the world, feelings of overall depression, and a pervasive sense of fear. In contrast, more positive themes were found by Hurlbutt and Chalmers (2002) where adults described valuing support systems offered through family and spiritual communities. Howlin, Goode, Hutton, & Rutter (2004) also found adult socialization outcomes were variable with some individuals having meaningful social relationships and others remaining isolated and dependent.

In our recent Ontario study of 480 youth (16+) and adults living with ASD (Stoddart et al., 2013), individuals with ASD and family members responded to questions about their social involvement. The findings support what was already described in the literature and highlight the lack of progress made in assisting young adults with ASD to become more socially involved. In open-ended questions about social activities and involvement, both family members and individuals expressed a desire for more social interaction juxtaposed with reluctance to participate in social activities, as well as feelings of social isolation. The majority (81.8%) of respondents indicated they had difficulties taking part in social activities; 73.7% stated that they did not find it easy to make friends; 60.9% indicated they did not have as many friends as they would like to have and 59.1% said that they did not find it easy to keep friends. A further 57.3% noted they did not have a “best friend”. Almost half the respondents (43.6%) noted that there were limited or no social programs/groups for adults in their community.

Of those respondents who reported social activity, 33.1% said that they engaged in on-line social networking; 32.1% reported they have had a romantic or intimate relationship in the past; and 14.9% stated they were currently in a romantic relationship. Many respondents reported a desire to be social and to have and maintain friendships. Individuals with ASD and communication challenges were even more limited in their social participation, as their limited verbal and behavioural repertoire acted as barriers to successful socialization. Participants’ responses indicated that the programs that do exist for this population tend to be part of day programs, or tailored to those with developmental disabilities, which are not suitable for individuals with ASD and higher cognitive ability. Finally, respondents indicated that the family served as the primary social network for many adults with ASD.

Challenges:

- Lack of early support for youth with ASD to prevent and address negative social experiences
- Lack of community-based opportunities for small group socialization for individuals with ASD at all levels of cognitive ability
- Lack of sufficient community-based leisure activities that can accommodate the special needs of adults with ASD
- Limited therapeutic supports to help young adults with ASD cope with social anxiety and take social risks
- Increased dependence on un-monitored on-line social interaction

Recommendations for the Community:

- Create a centralized resource guide of social opportunities for individuals with ASD
- Provide government funding for the creation and facilitation of small interest-based groups for individuals with ASD
- Expand funding opportunities to hire support workers who assist individuals with social integration in the community
- Create residential programs with an assisted living component that include facilitated social opportunities for adults with ASD with multiple, complex needs
- Create residential programs for students with ASD in post-secondary settings

Recommendations for the Individual and Family:

- Recognize that many appropriate social opportunities for adults with ASD can be found outside of treatment-based resources
- Prioritize participation in extra-curricular activities for individuals with ASD at all ages
- Identify social opportunities that capitalize on special interests (www.meetup.com is one resource)
- For students in post-secondary education, identify social groups for students with ASDs at the institution, frequently run through the Disability Office

- For students in post-secondary education, encourage participation in peer mentorship programs
- Encourage young adults with ASD to gain employment and/or participate as a volunteer in settings that include social interaction with others

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About the authors:

Barbara Muskat, PhD, RSW is Child and Adolescent Therapist at The Redpath Centre, Director of Social Work at the Hospital for Sick Children and Assistant Professor (status only) at the Factor Inwentash Faculty of Social Work, the University of Toronto. Her clinical and research interests include: addressing the social and emotional sequelae of Learning Disabilities and Asperger Syndrome, group interventions, and development and evaluation of programs to support parents of children with neurodevelopmental disorders.

Jason Manett, M.Ed, PhD (Candidate) is an Academic and Life Skills Coach at The Redpath Centre and Disability Counsellor at Accessibility Services, University of Toronto. He is also a doctoral candidate in the Human Development and Applied Psychology program at OISE/UT. His clinical and research interests include children, adolescents and adults with ASD, learning disabilities, ADHD, mood and anxiety disorders.

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