

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

The Importance of Life Skills

No. 63, July 2013

By: Priscilla Burnham Riosa, PhD & Claudia Accardi, MSW, RSW, The Redpath Centre



This article summarizes some of the information contained in the report entitled: *"Diversity in Ontario's Youth and Adults with Autism Spectrum Disorders: Complex Needs in Unprepared Systems"*.

Whether youth or adults are 'mildly' or 'severely' affected by an Autism Spectrum Disorder (ASD), deficits in adaptive skills (also called 'life skills' or 'functional skills') present challenges which are not well-understood or sufficiently addressed in our service system. Studies and clinical practice show that learning and use of these skills are problematic for individuals with ASD because of difficulties with generalization of learned skills from one setting to another, behavioural inflexibility, sensory sensitivities, gross and fine motor difficulties, mental health struggles, difficulties with executive functioning, lack of interest, and perceptual challenges (Kanne et al., 2011; Smith et al., 2012; Stoddart et al., 2013). Moreover, daily life skills challenges affect not only the life of the individual with ASD, but also his or her family and couple relationships (Stoddart, Burke & King, 2012).

Although research on life skills in youth and adults with ASD is relatively scarce, existing studies show life skills development needs to start early, transition planning is required, and continuous support in the young adulthood years are crucial (Smith et al., 2012; Kanne et al., 2011; Hendricks & Wehman, 2009; Thomson et al., 2011). With the acknowledgement of the significant role that functional life skills play in good youth and adult outcomes along with provision of appropriate life skills services and supports, functional skill development can continue throughout adolescence and into adulthood. A recent study investigated the

trajectories of daily living skills for adolescents and adults with ASD and found that "skills improved during adolescence and the early 20s, plateaued around the late 20s, and began to decline in the early 30s" (Smith et al., 2012, p.629).

In our study of 480 youth (16+) and adults living with ASD in Ontario (Stoddart et al., 2013), we gathered information on whether or not the individual required help with twelve life skills including: planning and preparing a meal, managing finances, attending to personal care, remembering schedules, arranging or attending appointments, using transportation, and finding and using services and supports. Overall, we found that services and supports in the area of adaptive skills were lacking and that an increased focus on family-centred supports is needed. Specifically, 81.1% of the participants reported that they always or sometimes required help with finding and using services, compared to only 15.8% of participants who did not. This finding not only speaks to the need for increased services for youth and adults, but also for supports to find and use services, and improved system navigation and self-advocacy skills.

In the same study (Stoddart et al., 2013), more than 50% of the participants reported that they always required help in several areas, including "paying and managing finances", "doing basic household repairs", "arranging and attending appointments", "dealing with mail and letters" and "shopping for clothes and groceries". These results reinforce the idea that when support for basic life skills is in place, the individual with ASD will be able to function successfully in his or her daily life, which also means being able to

manage medications, maintain a healthy lifestyle, seek and maintain employment, and pursue an independent life. The development of daily life skills is critical for successful outcomes for adults with developmental disabilities (Smith et al., 2012), and when planning for supports and services they must be individualized and needs-driven (Hendricks & Wehman, 2009).

Acquiring life skills is a life-long process that requires persistence, perseverance, and regular practice. Different strategies have been used to teach life skills to youth and adults with ASD, including: verbal, gestural, or physical prompting, reinforcement and/or praise, task analyses, error correction procedures (Thomson et al., 2011); role-playing social situations, scripts, making use of a hands-on “life coach” or “organizational coach” (Stoddart, Burke & King, 2012); pictures and videos prompts (Laarhoven et al., 2010).

Challenges for the Development and Maintenance of Life Skills:

- Sensory sensitivities, gross and fine motor challenges, and other diagnoses such as mental health problems may make participation in essential day-to-day activities challenging
- Participation in daily life activities traditionally motivated by social pressures may not appeal to individuals with ASD in the same way as those without ASD (e.g., household chores, personal hygiene)
- Dependency on family to support and perform many life skills may create chronic stress and worries related to the future of the individual with ASD

Recommendations for the Community:

- Increase person-centred funding and programs for functional life skills services and supports for individuals across the entire range of adaptive abilities seen in ASDs
- Create life skill resources, tools, and social networking opportunities for families and professionals to share knowledge and life skill training resources that include recommendations on how to foster basic and advanced independent living skills
- Provide a lending library that includes user-friendly life skill resources such as teaching tools, curricula, and assessment measures that can be easily accessed

by individuals with ASD, family members, and professionals

- Enhance training for teachers, educational assistants, support workers, behaviour therapists, and other professionals on how to teach adaptive skills with a specific focus on promoting personal independence
- Emphasize functional life skills as critical to success in the classroom and beyond; weave and highlight life skills training programs into academic programs and transition planning
- Conduct longitudinal research on the effect of functional life skills on individual and family quality of life
- Increase access to integrated residential and life skills support models

Recommendations for the Individual and Family:

- When choosing functional life skill goals, select ones that are personally meaningful to the individual and his or her family, and teach them early so that there is time to learn the skill (e.g., teach shaving before facial hair becomes coarse and long)
- Create goals that are appropriate given the individual’s strengths, personal preferences, and interests
- Select skills that are relevant to the current situation as well as geared toward potential future living situations
- Teach self-advocacy skills (e.g., asking for help, navigating and accessing services, safety) early on to promote choice-making and personal independence
- Teach functional life skills in the natural environment whenever possible to avoid challenges with generalizability
- Use individualized supports to learn and teach self-management and independence-related skills – e.g., activity schedules (pictures, text, video models), personal organizers, electronic devices, and apps
- Consider using the services of a life skills coach trained in task analysis and behaviour supports
- Seek assistance of friends and family members; however, distribute your requests to different people whenever possible to minimize the stress upon each individual in your support network (e.g., ask one

person to help with managing finances, and ask another to help with remembering appointments)

- Employ professional supports when feasible, such as a bookkeeper for help with financial needs, or a cleaning person/organizational coach to help with cleanliness and organization around the house

References:

Hendricks, D. R., & Wehman, P. (2009). Transition from school to adulthood for youth with Autism Spectrum Disorders: Review and recommendations. *Focus on Autism and Other Developmental Disabilities*, 24(2), 77-88.

Kanne, S. M., Gerber, A. J., Quirnbach, L. M., Sparrow, S. S., Cicchetti, D. V., & Saulnier, C. A. (2011). The role of adaptive behavior in Autism Spectrum Disorders: Implications for functional outcome. *Journal of Autism and Developmental Disorders*, 41, 1007-1018.

Laarhoven, T. V., Kraus, E., Karpman, K., Nizzi, R., & Valentino, J. (2010). A comparison of picture and video prompts to teach daily living skills to individuals with Autism. *Focus on Autism and Other Developmental Disabilities*, 25(4), 195-208.

Smith, L. E., Maenner, M. J., Seltzer, M. M. (2012). Developmental Trajectories in Adolescents and Adults with Autism: The Case of Daily Living Skills. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(6), 622-631.

Stoddart, K.P., Burke, L., Muskat, B., Manett, J., Duhaime, S., Accardi, C., Burnham Riosa, P., and Bradley, E. (2013). *Diversity in Ontario's Youth and Adults with Autism Spectrum Disorders: Complex Needs in Unprepared Systems*. Toronto, ON: The Redpath Centre.

Stoddart, K.P., Burke, L., & King, R. (2012). *Asperger Syndrome in Adulthood: A Comprehensive Guide for Clinicians*. New York, NY: Norton Publishers.

Thomson, K., Walters, K., Martin, G. L., & Yu, C.T. (2011). Teaching adaptive and social skills to individuals with Autism Spectrum Disorders. In J.L. Matson, P. Sturmey (eds.), *International Handbook of Autism and Pervasive Developmental Disorders: Autism and Child Psychopathology Series* (pp. 339-354), New York, NY: Springer.

About the authors:

Priscilla Burnham Riosa, PhD is Clinical Research Coordinator at the Hospital for Sick Children, Research Assistant, The Redpath Centre and a Behaviour Consultant supporting children and youth with ASD. She is also a sessional instructor at the University of Guelph-Humber and Brock University. She has worked with individuals with ASDs and their families for over ten years.

Claudia Accardi, MSW is Research Assistant at The Redpath Centre and Factor-Inwentash Faculty of Social Work, University of Toronto. Among various research projects, she is currently involved in a project examining the marital relationships in families of children with ASDs. Her interests include program evaluation, the use of technology in counselling, and research in ASDs, developmental disabilities, and learning disabilities.

DISCLAIMER: This document reflects the views of the author. It is Autism Ontario's intent to inform and educate. Every situation is unique and while we hope this information is useful, it should be used in the context of broader considerations for each person. Please contact Autism Ontario at info@autismontario.com or 416-246-9592 for permission to reproduce this material for any purpose other than personal use. © 2013 Autism Ontario 416.246.9592 www.autismontario.com