

# Transition to Life

## A MODEL FOR LIVING A GOOD LIFE FOR PEOPLE WITH ASPERGER SYNDROME



by Patricia O'Connor

**IN THE FALL OF 2012** Autism Ontario, in conjunction with Integrated Autism Consulting, applied to Autism Speaks for a Family Services Grant for this project. The application was successful and work on the pilot project began in January 2013. The course was taught at Georgian College in Barrie in June, July and August and the evaluation was completed in the fall of 2013.

### Project Description And Background Information

Transition from secondary school to life is one of the most stressful times in the lives of young adults, but for those with Autism Spectrum Disorder – Asperger Syndrome – the event is anxiety provoking and overwhelming. The intent of this project was to respond to the increasing needs of young adults in Ontario with Asperger Syndrome transitioning from the secondary school setting into independent living. There is currently a significant gap in services and supports for this population and direct support is required to develop the necessary skills to facilitate a positive transition experience and to prepare them for the next phase of life. Without support, individuals often graduate to the couch in their parents' basements and this is a waste of potential and will cost taxpayers \$3.2 million across the lifespan to support each individual. Transition to Life is a 12-week course that provides direct training and individual coaching support for young adults with Asperger Syndrome aged 18-28.

People with Asperger Syndrome often have incredible strengths. They are creative, unconventional, highly skilled and highly motivated in their areas of interest, have exemplary pattern recognition, focus, attention to detail, and extraordinary long-term memories that put our “neurotypical” minds to shame. They are honest, loyal, persistent and dependable. Since many of these individuals are also capable academically, parents often encourage them to begin college, university or a job immediately after graduation. Many are not successful for a variety of reasons but basically they are not ready. Often they do not have an understanding of the characteristics of Autism Spectrum Disorder (ASD) and how it affects them. Their emotional maturity may be four to five years younger than peers, and strategies to decrease anxiety and increase self-regulation are not yet developed. Since they are now adults, parent support is not tolerated and navigating a post-secondary setting wherein they are required to seek out a variety of supports can be problematic. Organizing, planning, and prioritizing are challenges, as is developing social understanding in the new setting. Strategies related to self-motivation for activities that are not of interest also need to be addressed, but most importantly these young adults need to understand The Value Proposition: what society expects from them as adults and how to perform within that context.

Transition to Life addresses these areas and provides direct training and coaching support for these young adults as they enter this most important phase of life.



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## Reflections

Transition to Life was an incredible experience for everyone involved. Twelve participants – six females and six males – were chosen to participate, with ages ranging from 18-24. While some participants were attending or had aspirations to attend post-secondary, others were seeking employment and some had had limited meaningful involvement in the community for a number of years. Extensive out-of-class support was required and individual coaching was an important component of the program, since individual needs were addressed during this time. In addition to coaching sessions, participants required e-mail or phone support for work completion. For the future, time for the weekly coaching sessions will be extended and format will be focused on reviewing and understanding course content. Individual coaching sessions based on personal issues will be available at another time.

Participation in class activities and coaching sessions was close to 100 percent. Although participants and parents signed a contract indicating their commitment to attendance, it was noted that they came earlier and stayed later after each class. Often they wanted to talk to their coach or make social arrangements with peers. All participants were involved in a volunteer experience or employment and two began their own businesses. An increase in the hours of the course is a goal for future courses as is a more in depth focus on employment skills.

Having an assistant or mentor with Asperger Syndrome is one of the cornerstones of the course. This individual was chosen based on their success in a post-secondary setting, their ability to provide information and support to participants from a first person perspective, and to assist with writing a portion of the content. Participants thoroughly enjoyed the involvement of someone their age and often sought her out as a mentor. Her contributions were very beneficial but additional time was required to support understanding of expectations, assist

with organizational skills and emotional regulation. She was an excellent addition and all courses going forward will have a mentor.

The development of weekly schedules with the addition of a new activity, based on the weekly content, was very beneficial. This activity became especially important for those that had been out of meaningful routines for years and for recent graduates who were beginning a new routine. For those with nocturnal schedules or for individuals who had no outside home involvement, resistance to use was evident since it imposed limits and restrictions. Although all participants

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had a meaningful schedule by the end of the course, the implementation and ongoing use is the unknown factor. Parent monitoring of schedule use and the implementation of all strategies is a necessary component for all future courses.

Since repetitive behaviours are a part of diagnostic criteria, it was not surprising that some participants exhibited

excessive behaviours that required attention. Although coaching could provide strategies to reduce some of the addictive patterns or overindulgence in preferred activities, some participants were referred to professionals for additional support. Next steps are to develop a network of skilled professionals that could provide additional assistance.

One of the observations that must be noted is that the individualized component of the program is expensive to offer. Although participants benefitted from many aspects of the large class, the individualized coaching is definitely required to reinforce information, clarify expectations and personalize the materials. Although this course was offered at no charge, families will need to make a financial commitment in the future. The question remains, will parents/individuals' pay a fee for this service?

## Participant Discussions: Hopes and Dreams

Each week participant discussions provided insight into their future hopes and dreams. Common themes about what characterized their success criteria for life began to emerge. First and foremost all but one wanted an independent living arrangement and the freedom to make their own choices and not be told what to do. Meaningful social relationships with



peers were another critical success factor. On many occasions I have heard the comment that individuals with Asperger Syndrome want to be on their own. While it may be true that they prefer more time alone, this was clearly not the case with this group of adults who were motivated to attend the social outings and make arrangements for others. It was heartwarming to watch relationships building and friendships being forged, many of which still exist today, almost a year after course completion. Daily activities that are motivating were certainly something that everyone discussed. Playing video games from dusk until dawn and sleeping all day may be considered the perfect life for the short term but many recognized that this does not make you feel good about life or yourself. A positive schedule increases confidence in your abilities and reduces anxiety, which often comes with the AS territory. All were concerned about future employment opportunities, but the

participants in their 20s were more focused on this discussion. Many expressed concerns about their post-secondary experiences, indicating that they didn't know when to ask for assistance and by the time they did it was often too late. Another concern was the number of support staff and the inconsistent delivery of services. Some parents noted that their ability to assist by speaking to the college or university staff was often thwarted with comments indicating that their child was an adult and needed to take care of their own business. Others were about to graduate from college with few known prospects for employment. The general message: individuals with Asperger Syndrome have many of the same hopes and dreams as other young adults but require a concentrated level of support to navigate the challenges and successfully transition to the next stage. The Transition to Life program is not just a course but the foundation for a positive

lifestyle. A final but important note: All participants, but one, are currently employed or have completed the past year in a post-secondary setting.

### Research and Evaluation

Pre- and post-assessment documents were completed by participants and parents. A summary of findings was prepared by the Chair in Autism Spectrum Disorders Treatment and Care Research at York University. This is a brief synopsis of findings and the completed summary is available by request.

"Parents and students completed a validated scale of adaptive behaviour which speaks to the level of independent skills the student has across a number of conceptual, social and practical domains. Overall, results were striking in that far fewer students assessed their skills as being far below what would be expected of others their age overall – only three out of the 12. In contrast, parents viewed their children's level of need as far greater, with six out of 12 being in a range below age expectations. The underestimation of need by the students with ASD may speak to difficulties in gauging their capabilities accurately; speaking to the importance of receiving informant report and to helping them accurately determine their strengths and weaknesses in an assessment prior to the educational planning process."

Improvements were noted in pre-work preparation and readiness as well as work readiness, and a trend showing improvements in depression over the duration of the course. There were no changes in ASD symptoms. Students and parents rated their satisfaction across the entire program using the Client Satisfaction Questionnaire. Nearly all students were very satisfied with the course, while parent ratings were higher across many topics.

### Update

In the fall of 2013, Autism Ontario and Integrated Autism Consulting again applied and received funding from the Ministry of Economic Development,

## Testimonials

"Before Transition to Life, I was insecure, unhappy, and doing the same routine everyday. I felt alone, like no one understood me. So I would live in my own little world. After Transition to Life my life has made a turn for the better. My confidence and independence has literally sky rocketed. I've learned more in three months doing this course than most people with ASD would take an entire year to accomplish. I guess that scared insecure girl I once was is gone. I think that every adult with ASD should take this course." *Ashley*

"This program was wonderful! Our son has gone back to university with a sense of control and optimism. He is determined to follow the schedule and advice that he learned from the program and has successfully hit the ground running. This has also shown itself in his renewed efforts at maintaining his personal hygiene. He loved the program. He met new friends. He hopes to keep in touch with his coach and instructor Pat. Overall we couldn't have asked for a better experience for him! I would recommend this program to any young adult on the spectrum (or to their parents). Thank you to everyone involved." *Cathy*

"The amount of independence and confidence that taking the Transition to Life course has instilled in our daughter/sister is absolutely phenomenal. Being around people that genuinely cared about her progress and well-being has not only benefitted her by opening doors in the community for jobs and support, but also has motivated her to take steps in life that she didn't even know she was prepared to take. This course is an answered prayer for any youth on the spectrum that want a little love and support in an ominous society where support is scarcely given where it needs to be." *Kim*

Trade and Employment (Youth Skills Connection Grant) to expand the program to different parts of the province, and to further develop it with a specific focus on finding employment. We are grateful for all of this support and undertake the challenge with enthusiasm!

“Transition to Life College (TLC) is an interactive, individualized life/employment preparation program for individuals with Autism Spectrum Disorder (Asperger Syndrome) aged 18-28 who require support with the transition from secondary school to adult life and preparation for work or post-secondary education.

This two-part series integrates key teachings, experiential learning components and individualized coaching throughout the 12 week program with the primary goal being supported and/or paid employment.”

*Patricia O'Connor is the author of the Transition to Life program and the founder of Integrated Autism Consulting. The vast majority of her work revolves around supporting young adults with Autism Spectrum Disorder-Asperger Syndrome in work, school, social and transitional situations. She is in constant admiration of their ability to view the world through a different lens, to persevere through the darkest hours and of their unwavering dedication to finding and maintaining meaningful relationships.*

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## Moving On

### NEW GUIDE EASES TRANSITION TO UNIVERSITY OR COLLEGE



by ??? 

**THE REGIONAL ASSESSMENT AND RESOURCE CENTRE (RARC)**, based at Queen’s University, has created a comprehensive guide to help students with disabilities successfully transition from high school to university or college.

The *Transition Resource Guide*, developed with funding from the Ontario Ministry of Training, Colleges and Universities, is a one-stop repository of information to help students navigate the transition to post-secondary studies and access the services and supports they need.

“Starting university or college can be a difficult transition for any student, and a disability can bring additional challenges,” says Marie McCarron, Clinical Manager at RARC. “Regardless of whether there is a learning, mental health or physical disability involved, the Transition Resource Guide offers valuable information to help students through the entire process, from making an application to getting the services they require once they arrive on campus.”

The guide includes general information on topics such as selecting a college or university, scholarships and bursaries, and disability support services. It also makes it easier to navigate the resources available at each of Ontario’s universities and colleges by providing specific information about each institution and their disability and accessibility services.

The guide was created with input from a variety of stakeholders, including

