

A Good Life: Critical Success Factors for Adults with ASD

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In the next 5-10 years thousands of children with ASD will leave the school system and enter the world of adulthood. This should come to us as no surprise since the diagnosis has increased considerably in the past decade with the prevalence rate of Autism Spectrum Disorder (ASD) being 1 in 110. In Ontario, there are an estimated 100,000 individuals with ASD (Autism Ontario). The question in the minds of many parents and professionals now is how we ensure that our young adults lead a good life. The definition of a good life may vary from person to person and family to family, but most can agree that independence, meaningful relationships and employment would factor into the equation.

The following account/interview is from a middle-aged man with ASD that has been involved in life's adult journey for some time now. It is the story of my brother and how he, with supports, has maneuvered life's challenges in a formidable manner to experience an independent, dignified and meaningful life.

Background Information

Christopher is 39 years old and he enjoys many different activities. His favourite foods are steak, spicy chicken wings, pizza, Chinese food and poutine and he likes to drink iced tea, Monsoon Mai Tai's, Shirley Temples and beer. His schedule is a little different every day but usually involves sleeping in (since his job ends at midnight), seeing friends, doing household chores and taking part in some of his favourite activities: biking, fishing, swimming, computers, video games and movies. Chris loves dogs. He gets around by bike and by city bus.

Making his own choices is really important to Chris and he makes many of them every day. He decides who to spend time with and what

they will do. He decides when he will do things and what food he is going to eat and how his day goes. He makes a lot of his own plans and decisions and that is the way he likes it.

Structured Schedule

A structured schedule is necessary for all individuals leaving the school setting. Even though school may not have provided all of the skills that are necessary to undertake life's next steps, it did provide structure. A schedule involving work, (volunteer, self-employment and/or competitive employment), community involvement, social relationships, leisure time and opportunities to reduce anxiety by being physically active are all necessary components of fulfilling lives. On many occasions, individuals across the spectrum transition from school into their parents' homes full time. This can be devastating for all involved since apathy, malaise and idleness lead to depression and hopelessness. Once these patterns become the "new normal" they are difficult to change. It is essential that our young adults move into an active level of involvement outside the household with increasing steps towards independence. Chris has had this experience and it has been extremely beneficial.

Social Life

Chris has 4 or 5 friends who he sees often. All of these friends have some challenges but they all live by themselves, in a supported living situation, except for two people who live with their parents. He sees one couple twice a week for supper and gets together with the others for biking, "hanging out", going to the mall or going out for supper. He has known most of his friends since he was younger and he thinks friends are supposed to stick together, do things

together and do favours for one another. He has had lots of disagreements with friends and he was not quite sure how they got resolved but they keep getting together.

He has had some bad experiences with people that didn't turn out to be friends. Sometimes they borrowed money or his possessions and didn't return them. He doesn't talk to those people any more.

Housing

Chris has lived in 3 different places in his adult years. He has lived at home, at his "old place" for 13 years and in the place he is in now. He really liked his previous place since it was in a house and had lots of room: a kitchen, living room, bedroom, bathroom and a large porch. The landlord was good and Chris helped around the house with shoveling, garbage and odd jobs. The rent was cheap and he could walk to the grocery store and other stores, too. The new place is a bachelor apartment in a basement and is OK. It is farther from everything and really small but it is comfortable. He has had to store most of his belongings and would like to get them back. He does not want to move again because the last move was stressful but in the future he would like to get another place that is bigger and closer to work. He has been on a waiting list for subsidized housing for 4 years.

Community Involvement

Chris has been involved in Special Olympics for most of his adult life. His main sport is Nordic skiing. He has competed at national and international levels and won two gold and two silvers in Saskatoon in 1992 and gold, silver, and bronze in Austria in 1993. He began skiing at the age of 6 and continues to ski weekly throughout the winter months. He loves to do it on his own and enjoys watching for woodpeckers and animal tracks. He also curls every Sunday during the winter months and sometimes the team competes out of town. Track and field, swimming and power lifting are other sports that he has been involved in.

Anxiety Reduction

Medication has been part of his life for many years but the best things Chris does to keep calm are exercise, listening to music, seeing friends and sometimes being alone. He occasionally rides his bike for long distances. He is not getting any counseling

at this point, but has in the past. He thinks that it is really important to keep a positive attitude.

When Chris was younger he had many sensory issues related to all modalities: sight, sound, touch and smell/taste. Malls presented huge issues with loud sounds, too many people and wide-open spaces. At 39, many of these issues have diminished but loud noises (such as babies crying) are difficult to cope with so he tries to ignore them and get away from the source of the noise. If he is at work, he leaves the room.

Employment

Chris has had many jobs since high school. These included: a convenience store where he stocked shelves; a restaurant where he washed dishes and cleaned; a police station where he worked as a janitor and was treated well by other staff; A truck stop where he washed dishes (he found this job stressful because it was very busy, never-ending and the people were sometimes hard to deal with); a pizza shop where he cleaned and made pizza dough and assembled boxes plus got a free meal every day and at a retirement home where he worked as a janitor and found the residents and staff friendly. Chris found all of these jobs through Community Living.

Currently Chris works as a janitor at the bus station. This is a regular job paying minimum wage. There are positive and negative things about the job. Some of the people can be very rude and he has to deal with mentally ill people and people who are drunk and stay there a long time. He knows some of them now and they are getting better but sometimes he has to get a bus driver/supervisor to help him out because he states that, "he is not great at dealing with the public issues". Most of the bus drivers are nice and helpful except one that he has decided to totally ignore. Sometimes he has to clean up big messes as part of the job. There are lots of good things about this job. He gets to work on his own and he really likes that. He gets paid well and works part time. At a later date he may want to work full time, but for now part time work is OK. He likes his boss because she gives warnings about changes in the schedule and gives him really good holidays.

At every job, Supported Employment, through the Community Living Association has been available to help. The workers change frequently but if Chris has a work related problem he can go to them for assistance. Over

the years, Chris has had some challenges in the workplace, but he has learned many social and communication skills. He is a hard worker, reliable and has a very low absenteeism rate all of which have contributed to his success. Other positive characteristics that Chris exhibits are determination, adaptability – now, courteousness, a friendly nature, honesty, optimism and sincerity.

Supports

Although Chris leads a very independent life, he has sometimes needed and received help from other people in a variety of ways. Mom helps him with lots of different issues that have happened over the years. She lives in the same town and Chris sees her every Sunday for supper. Chris likes to go on vacations to visit his sisters and brother and his niece and nephews. He texts them on a very regular basis. He goes to the cottage with his mom for two weeks in July and in August every year. Supported Independent Living (SIL) Program helps when finances, forms or household activities are causing difficulty. They come to the apartment once weekly to discuss and help him solve problems. Friends and people he knows will provide support if he asks for help.

Hopes and Dreams

What are your dreams for the future?

“Maybe I’d like a full time job and a better apartment. I’d like to get a job fixing computers or something to do with computers in a computer store. I might want to get a scooter. I want to try scuba diving and see all the different kinds of fish, go swimming in the ocean and travel to some tropical place.”

Conclusions

After talking to Chris about his life it became evident that all human beings have the same needs whether or not we have ASD. We have a need to contribute to society, have friends and have fun. We have the need to be as independent as we possibly can and that makes us feel good about ourselves. The components of a

good life for individuals with ASD are not difficult to understand but the supports and guidance required to ensure that this occurs is the key to success. These supports are often not available. As government supports diminish, and the number of individuals with ASD entering adulthood continues to increase, all sectors of society must find innovative ways to support this vulnerable population during this challenging transition. This will ensure that these capable individuals have opportunities to demonstrate their skills and live an independent, dignified and meaningful life.

“The best part of life is that I don’t have to worry about anyone but myself. I do what I want, when I want to and the best thing of all is that I am very independent.” Christopher O’Connor

Pat O’Connor has been involved in the field of ASD almost all of her life. She is currently focusing on consultation, coaching, advocacy, training and program development for young adults with Asperger Syndrome transitioning into life. Her company is Integrated Autism Consulting and she can be reached at patriciaoconnor@rogers.com.

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