

INTRODUCTION

There is a notion that once you become an adult you reach independence, but are any of us truly independent? We rely on others to teach us things we don't know, seek professionals to deliver services we can't do ourselves, have a network of friends and family for support, live in a neighborhood, and work in a community. In other words, the lives we lead as adults are interdependent, not independent.

Adult life is more complex than childhood. For individuals with autism, becoming an adult does not mean the struggles in childhood have disappeared – they are just different. Social struggles on the playground may now be in the workplace. Misunderstandings in friendships have moved to intimate relationships. Doing a few household chores when living with parents has morphed into managing the entire home when living alone.

The main focus of adulthood on the autism spectrum should be how to live a meaningful life and achieve happiness and wellbeing. What does that look like for each individual? Because skills and ability vary so widely, for some this may mean being successfully employed or living alone. For others, it may mean attending a day program they enjoy, volunteering or living in a supported environment. Everyone needs recreational opportunities, ways to connect with others, and the chance to pursue passions and interests. There is no right or wrong answer – it's about what is best for the person.

Adulthood may also be a time of self-discovery, asking the questions, “Why am I different? Why do I feel out of step with the world around me?” Pursuing the answers may lead to a diagnosis later in life. Although many adults feel relieved about receiving a diagnosis, it also means a whole new way of defining oneself and having to defend a diagnosis. To adjust, a person may need the help of a professional or a support group.

Transitioning from school to adult life is a big leap - one that requires several years of planning. It takes time to explore further education, community programs, leisure activities, and social opportunities. The move from pediatric to adult services means choosing a new doctor, dentist, specialist, and support service system.

Individuals with autism remain vulnerable in adulthood, which is why a team around the adult is necessary. They need the continued support of family, friends, people they can trust and a community that knows them to feel secure and safe. This circle of support is essential because parents will not always be there, so others are needed to continue in a caring role.

Support will always be changing and evolving as the years go on. Adults change as they grow, expand their interests, develop new skills, change jobs, volunteer, move out, and age. Life never remains static. Success in adulthood depends on a network of supportive people, resiliency, advocacy, determination and having choices in life that make a person feel happy and fulfilled.

Sincerely,



Maureen Bennie

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LIVING THE GOOD LIFE

A MODEL FOR SUCCESS

One of the greatest fears a parent of a child with autism has is how and where will their child live when they are no longer able to take care of them. What will their adult lives look like? How will they spend their day? What does a meaningful life look like in adulthood?

I attended an excellent presentation given by Neil Walker of [Kerry's Place Autism Services](#) (KPAS) located in Southern Ontario. Neil described the KPAS philosophy which I'd like to share with you because it has been a big part of the KPAS success story and positive outcomes for those with ASD. Their values could be adapted to any new organization wanting to provide services for adults or be the guiding principles of what parents should be looking for in order to ensure a high quality of life in adulthood.

The KPAS vision is that people with an ASD are accepted as full and equal members of their communities. The key word here is “their” not “the”. In order for a person with ASD to be included, they have to have a meaningful place within their community. Every person has the right to make informed choices. Interactions need to be truthful, accountable and ethical with that person with ASD. The community as a whole has to work together – families, staff, funders, community partners, and other stakeholders. We have to respect the dignity and uniqueness of all people.

We need to foster a continuum of support, not of care. What’s the difference? A continuum of care is where everything is done for the person with ASD such as cooking, household chores, decision making and daily needs. The continuum of support lets the person with ASD do things for themselves but provides the necessary supports in order to ensure success. You want to build skills and create opportunities for continuous learning. The goal is to move from the least independence to the most independence, no matter what the functioning level is. This will also go hand in hand with moving from the lowest quality of life to the highest. Independence lessens anxiety and depression because the person feels that they have a say in their life and some control over it. It’s all about being able to make choices that suits them, not what we think is best.

KPAS provides training and skill fostering geared to each individual’s needs. Their emphasis is on environmental considerations and communication skills. An outstanding feature that they have added to residential life is a professional Liaison. The Liaison’s role is to coordinate the individual’s support and communicate with the family. They are, in essence, the individual’s advocate, overseeing all aspects of their well-being. This personal connection creates a true caring relationship that is built over time.

When thinking about residential accommodations, there will never be one model that fits all diagnoses. Even within similar functioning levels, there can be a great variance of skills or support needed. One option for living could be with an associate family where the individual lives within another family’s home and the family provides some support. They would have their own self-contained living space. In Supported Independent Living, the person lives on their own but has a support worker who visits them as needed, like perhaps once a week or once a month. Multi-plex living is a 4-plex with individual suites in it but some people may have a roommate if they would like one. The 4th suite is for a full-time support person to live in, overseeing the 3 other suites. Group living consists of a maximum of 4 people in a dwelling, each with their own room but some shared common spaces.

The key to any of these living situations is individualization. Neil showed us two DVDs of very different individuals and how they were living. The eye-opener for me was seeing a non-verbal young man living in his own self-contained suite. He had support, but was able to do so much for himself, more than you would think from just looking at him. His parents expressed how happy their son was and how much better he was doing living on his own. When he was at home, they were restraining their son in a bed due to his difficult behavior. Restraints are now a thing of the past for him.

Community living supports are another aspect of adult life. These encompass meaningful day supports (social, recreational, and daily living activities), work experience and volunteering, vocational training, employment or adult education. The person with ASD has to be participating in their own life to be living a life. To achieve adult status, we have to stop treating these individuals like children.

Finally, I would like to list the KPAS Operating Principles for Individualized Support. There are 14 of them:

1. People first- it's people with autism, not autistic people.
2. Assume competence – most people with ASD have greater abilities than they may be able to demonstrate.
3. Supported individuals are treated with dignity and respect appropriate to their age.
4. People with ASD have the same rights and responsibilities as anyone else living in the community. People with ASD must be taught both of these aspects.
5. Do no harm/protect from harm.
6. Support by doing with, not doing for. See each activity as a learning/teaching opportunity for developing greater skills towards independence.
7. Develop self-management skills. Learning self-control facilitates future independence.
8. Value interdependent participation. A good quality of life is achieved by supporting people to participate in activities, even if they need assistance to do so.
9. The supported individual with an ASD is always the centre of service planning.
10. To move from a high level of support to a lower level, risk taking and risk management is involved.
11. Value age appropriate and interest appropriate activities. The individual may need to be taught how others perceive them when engaging in age inappropriate activities; however, people have a right to engage privately in their interests regardless of public perception.

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