

Who Will Take Care Of Our Kids (When We No Longer Can)?

The Challenges Facing Adults with Autism Spectrum Disorder and Their Aging Parents

Discussion Paper

Prepared for Autism Society Alberta (ASA)

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The opinions expressed in this report are based on the authors' interpretation of what was heard.

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EXECUTIVE SUMMARY

In September 2016, the Autism Society Alberta Board of Directors funded the project "Who Will Take Care Of Our Kids (When We No Longer Can)?" The purpose of this project was to further the Board's understanding of this issue. Thirty-four stakeholder interviews were conducted, and three questions were asked of each stakeholder:

1. What currently exists to ensure a sustainable quality of life for adults with ASD?
2. Where are the gaps?
3. Are there any innovative ideas or new models?

Stakeholders gave examples of housing models that were working for some: host families, family-owned homes with government support, supportive roommates, and communities of faith that have created housing. There were also other examples of housing models, like co-op living. Stakeholders noted programs to address the issue, such as the concept of a network of people who voluntarily agree to support the individual for life, government funding for those who are eligible (AISH, PDD, RDSP), government services (public guardian), Canadian and provincial coalitions that are working specifically on this issue, and the importance of a support plan or template to pass on detailed information to new caregivers and guardians.

The most common gap noted was that parents are not planning ahead. Stakeholders noted that some aging families do not even have the basics in place, like an appointed guardian or a will. Other gaps included:

- The lack of quality housing, which has resulted in growing wait lists
- The cliff that people face when the individual turns 65
- The lack of caring, trained and available staff
- The lack of public awareness of challenges faced by aging families, and
- The lack of mentorship for families and individuals to connect with those who have succeeded in creating a sustainable quality of life.

Overall, many services that already exist were not known by families or agencies. Good ideas are not easily accessible. The system of support is fragmented, unintuitive and difficult for parents to navigate.

New innovations are emerging in areas of technology to enhance independent living, insurance system approaches, and the use of mentorship programs to help others create lifelong quality models. The concept of a one-stop coordinator where all relevant information and support exist is also being discussed.

Through this work we discovered key practices that, when used together, are one step towards addressing the issue of sustainable, quality, life-long support. These key practices include:

- Creating a network of committed people for support
- Planning early
- Enhancing financial security through RDSP contributions and discretionary trusts
- Accessing home settings with high-level qualified agency staff who work in collaboration with families
- Ensuring communication through ongoing care and support plans

These outcomes are complicated and time-consuming for families to achieve. For some families, they may be impossible. Improved information access and better support for families navigating the system, plus increased public awareness and enhanced system capacity, are among a few of the answers moving forward.

WHAT IS THE PROBLEM?

Most typical parents rarely give thought to what happens to their adult children when they are no longer able to support them or when they are deceased. Most families see their children become adults, completely independent in all aspects of life, and in many cases the children end up caring for their aging parents. This is the normal aging process. But for families with a dependent adult living with ASD, the support and care dynamic is inverted. Aging parents often continue to provide support for

their adult with ASD well into their retirement years. This is problematic, because as parents of dependent adults with ASD age, they will be unable to sustain efforts of support. Not only is it challenging to be a lifelong caregiver and advocate, but parents are also living with this agonizing question of “What happens when I am gone?” Many do not want to solely rely on relatives or the other surviving children, but have no idea what is needed or where to start.

WHAT DOES THE RESEARCH TELL US?

Research indicates that many adults with ASD live at home with aging parents. In a study from Ontario of 480 adults with ASD, 60% lived with family (Stoddart, 2013). In a study following 76 children with autism born 1974-1984, researchers found that 56% lived with parents, 35% were in supported living (group home or foster care), and only 4 individuals of the 76 lived independently (Eaves & Ho, 2008). Many adults with ASD remain highly dependent on family, and compared to higher-functioning individuals with other developmental disabilities, those with high-functioning ASD are less likely to achieve independent living (Levy & Perry, 2011).

Many adults with ASD, regardless of level of ability, need lifelong supports. A survey of 480 individuals with ASD ages 16 to 66 found that more than 50% of adults needed help with tasks of daily living, such as household chores, attending appointments, managing finances, and finding services. Thirty percent of those surveyed needed help with personal hygiene, dressing, transportation, and the very basic skills of living (Stoddart et al., 2013). In an American survey of 143 families caring for an adult with autism, 58% of adults with ASD needed help with activities of daily living (toileting, bathing, dressing), and 84% needed help with auxiliary daily living skills like bill-paying, cooking and cleaning (Graetz, 2010).

Although some aging ASD families might not specifically identify themselves as a disadvantaged population, the unfortunate fact is that many experience negative physical and mental health and financial consequences resulting from the autism diagnosis. Parenting an individual with autism is associated with reduced quality of life and high lifelong levels of stress, depression and anxiety due to the nature of care required (Cachia et al., 2015, Barker et al., 2011). Research clearly confirms that lifelong

caregiving can result in poor health for caregivers (Vitalino et al., 2004). Elderly caregivers of individuals with developmental disabilities, including ASD, frequently experience stress that can develop into a more serious illness (Lovell & Wetherell, 2011). Mental health issues like anxiety and depression are also more common among caregivers, as is caregiver isolation. This is especially common when the care recipient experiences challenging behavioural issues, or when families are of a cultural minority (Heller et al., 2007). Mothers of individuals with ASD reported significantly more time spent on care and chores and less leisure time compared to a sample of mothers of children without disability (Smoth et al., 2012). Lifelong caregiving is very stressful, and in the context of unprepared support systems, is not sustainable (Rowbotham et al., 2011).

Many caregivers struggle under the excessive financial burdens which start from the time of ASD diagnosis. Xiong and colleagues (2011) found that the total amount of annual financial burden was highest for families who had a child with autism. Autism was a significant predictor of family spending in areas of education, medical care and caregiving. In another study, demands on the ASD caregiver's time resulting in decreased family earnings by 21 percent in comparison to families of children with other health limitations (Cidav et al., 2012). Caregiving was a full-time job for 90 percent of caregivers of adults with developmental disabilities (Dillenburger & McKerr, 2009).

The closure of institutions which housed most individuals with developmental disability years ago was a welcome change, but with the complete move of care into the community other challenges have arisen (Mansell, 2006). In some cases, young adults are placed into long-term care settings with elderly clients, where they receive inappropriate services for their age.¹ Despite the increased focus on the issue of long-term care and housing options for the aging Canadian population, one issue remains problematic: the housing of young people (under the age of 65) living with disabilities in long-term care institutional settings, where they often reside for decades (Blomqvist & Busby, 2014).

¹ <http://www.cbc.ca/radio/thecurrent/the-current-for-july-9-2015-1.3144401/placing-young-disabled-people-in-nursing-homes-not-right-say-families-1.3144446>

In a review of living circumstances for children and adults with developmental disabilities in five countries, including Canada, the researchers report that none of the countries reviewed had housing considered adequate to meet the needs and demands arising (Braddock et al., 2001). The complete move to community care places the lifelong burden of care on the shoulders of aging families. The impact of deinstitutionalization has left a gap in the safety net, especially for those with challenging behaviour (Allen et al., 2007). The entities responsible for the care of those with severe disability in the home have not always shown adequate concern for the impact on aging caregivers (Cummins, 2013). Wait lists for quality housing for those with developmental disabilities are considered to be at a crisis level (Developmental Services Ontario, 2013).

Accessibility of housing and lack of community infrastructure are not the only issues – the lack of quality is equally problematic, as well. Even if a group home placement can be found, another issue is frequent dissatisfaction with group homes (Mansell, 2006). In a qualitative study from the UK on aging caregivers for adults with a range of lifelong disabilities, the theme of finding suitable long-term housing and care options was one that united almost all caregivers who participated in the study. Concerns exist for group homes on lack of staff training, inconsistent quality of care, staff attitudes, and institution-like environments, all cited as problems in group home settings (Manthorpe et al., 2015). Manthorpe and colleagues note that parents were often still involved in supporting the arrangements or acting as a safety net when things went wrong.

Aging parents are very concerned as to where their loved ones will live and who will take care of them (Developmental Services Ontario, 2013, Calgary Regional Community Board, 2012). The lack of available quality housing puts undue stress on caregivers who have lived lifelong with the extraordinary demands of supporting a child, adolescent or adult living with neurodevelopmental conditions like ASD. The heart of the debate is how to provide clients with quality, accessible lifelong support, including housing programs, that can help them reach optimal functioning at a reasonable cost (Van Bourgondien & Schopler, 1990). Although this article was written decades ago, the same issues persist.

Examples are available of good-quality group homes for those with ASD. In the review of a group home model in North Carolina based on a unique autism model

called TEACCH, researchers examined cost-effectiveness, staffing, training, structure, programs, philosophy and administration. Results showed that group homes can be viable and cost-effective, but that there are not enough available, which results in multi-year wait lists (Wall, 1990).

The prevalence of ASD has risen dramatically since the 1970s (Lowe et al., 2014). The cost of unpaid caregiver time in Canada by middle-aged and older unpaid caregivers indicates that caregivers contribute much to the Canadian economy; often they do so willingly (Hollander et al., 2009). However, when they have done so for a lifetime and are unwilling or unable to continue, there must be better options to ensure quality, life-long, and sustainable supports.

PROJECT METHODS AND FINDINGS

To better understand the issue of sustainable quality of life, a stakeholder consultation was selected as the primary source of information. Thirty-four stakeholder interviews were conducted over several months with a range of agencies and individuals, including service providers, professionals, researchers, government agencies, parents, caregivers, and self-advocates living with ASD. Interviews were conducted over the telephone and in secure settings. All stakeholders agreed to be interviewed, and all were asked to provide signed consent to have their names and organizations noted in Appendix A. The initial stakeholders consulted were individuals suggested by the ASA Board as persons who had an important role to play in the Alberta adult disability community. Through these interviews, other key stakeholders were identified, and interviews continued for the time allotted in the project. Information from the interviews was reviewed to identify common themes.

Three questions were asked of each stakeholder:

- What currently exists to assist aging caregivers and individuals with ASD to ensure a sustainable quality of life?
- What are the gaps that exist in ensuring sustainable quality of life?
- Are there any innovative ideas or new models that address this issue?

WHAT CURRENTLY EXISTS THAT IS WORKING?

When stakeholders were asked this question they noted a number of concepts, initiatives, and services that were working for some individuals. Although this project was not focused specifically on housing and wrap-around services², access to housing models that provide this support is integral to this issue. Other ideas that are working for some include:

- The concept of a network of support people surrounding the individual
- Certain government supports
- Financial supports
- A number of provincial and federal disability coalitions working on this specific problem
- A template for communicating all support needs, and
- Supports for families.

Examples of Housing That is Working

Programs using the host family model (also known by the name of home share or supportive family) are well-established in British Columbia and Ontario, but less so in Alberta. In this model, an unrelated family agrees to provide housing and support for the individual with disability for a specified amount of time. The hope is that the host family model is mutually beneficial, as the host family has a rewarding experience and the individual with disability is able to develop stable long-term relationships and initiate positive new experiences that are comfortable, interesting and enjoyable. In British Columbia and Ontario the host family program is a government-funded initiative that helps partner agencies match pre-screened host families with an individual with a developmental disability. In Alberta there is no official government structure for this model, but there are instances where families have used the similar supportive family model. In terms of sustainability there are some drawbacks to a

² Wrap-around services are considered the support services that surround a family and individual to create a good life. These could include, but are not limited to, transportation, mental and medical health services and recreation.

host family model to consider. One in particular is the situation where the host family is no longer able to provide support, at which point the individual, government support worker or aging parent must then find another matched family.

Another stakeholder described a unique and innovative partnership between their family, the government and an agency that provides a model of care simulating a home. In 2009, this family purchased a home and renovated it to meet the needs of their son with special needs. Parents, government and agency collectively addressed the needs of each partner, resulting in the home offering 24-hour care for medically fragile children, with two permanent beds and one short-term respite bed. As a group, the partners established the criteria for occupancy. The agency provides all aspects of operating the home, including staffing.

“Families need to be able to provide input into whatever model they use, as they know their child best.”
– Stakeholder Quote

Another stakeholder discussed the concept of supportive roommate model for a higher-functioning person with ASD. Using this model has allowed this individual to develop independence to the point that, with the help of his family, he owns his own home and is living on his own.

“A supportive roommate really works for some. In this situation, it took years to develop, but he is completely independent now.”
– Stakeholder Quote

Intentional communities like the Reena Community Residence in Vaughan, Ontario integrate home supports, programs and recreational activities to offer individuals with varying disabilities an opportunity to live in a truly inclusive environment – a community where they can live, work and play. In the United States, in places like Florida, intentional villages are becoming more common, bringing together community supports and services with affordable housing to demonstrate how different types of communities can coexist and offer all residents a good quality of life.

Communities of faith that build housing supports are one area that warrants further investigation. Across Canada and worldwide, housing models for people with disability have been created by communities of faith. The benefits of these models and their success could be related to a strong network of financial donations and the values of caring and a commitment to helping others that exist in communities of faith. Due to the time limits of the project, we were not able to expand this investigation.

In this project, L'Arche Calgary was interviewed as part of an international organization that offers individuals with disabilities a model of care within a spiritual context. L'Arche Calgary homes pair people with and without disabilities who want to share a life together. Unfortunately, the wait list for placement can be very extensive, as L'Arche Calgary currently has a limited number of homes.

“These homes are unique in the sense that, unlike other group living situations that have rotating staff, L'Arche homes have live-in assistance. Staff are intrinsically motivated to share their lives. The human side of the job really benefits the individuals receiving care, as, in essence, everyone becomes a family.”

– Stakeholder Quote

European housing models of sustainable quality of life for those with developmental disability are also of interest. Unique designs and policies were noted by several stakeholders. Some ideas are translatable into a Canadian context, while others, due to differences in political systems, policies, cultural values and historical roots, are not. Although these ideas may not be feasible in Canada, they are of interest in terms of stimulating discussion on possibilities. Co-op community housing does exist to some extent in Canada, but the idea has truly flourished in Europe. We were not able to do an in-depth investigation into European models due to time constraints on the project, but Europe does offer some interesting examples. In a small town in England, there is a government-supported cul-de-sac model with bungalows that house individuals with varying degrees of disabilities. The local borough council in that community is an active partner, ensuring that the quality of life of the bungalow residents is maintained and secure. In Denmark a stakeholder noted that a local

government council can be fined if they cannot find appropriate housing for an individual with a developmental disability.

“Europeans’ core values seem to be centered on what is good for everyone. It appears that they consider what works for an entire community, and that everyone has equal rights.”

– Stakeholder Quote

Quality sustainable housing is critical to finding a solution. As noted above, community living is working for some, but not for all. Unfortunately, significant barriers to quality sustainable housing are discussed in the next section on gaps. Please see Appendix B for further information on housing models.

Concept of a Network of Support

The concept of creating a natural support network surrounding the individual with disability was also noted by stakeholders who have been working in this field for many years. The concept of this network is that it be comprised of family and friends or individuals that enter into the network freely. This idea has been led by the Planned Lifetime Advocacy Network (PLAN) in Canada. PLAN affiliates exist across the country and offer services to pan-disability families. Different affiliates in different provinces appear to take slightly different approaches, such as offering a paid lifetime membership for the family, having a paid core coordinator who oversees the creation of the network, or with no fees charged. PLAN has also authored a book entitled “Safe and Secure” (see Appendix B) that outlines 6 steps to creating a good life for people with disabilities.

A variation on this network model was found in British Columbia, where families have the option to create their own microboards to support their child or adult with a disability. A microboard is a formal non-profit society made up of committed family and friends who help an individual plan a life course, and can become an entity through which paid services and supports are provided. The main difference between these two models is that a microboard is incorporated as a nonprofit

society. In British Columbia, PLAN and Vela Microboards work together, and some families belong to both.

Government Supports

Government services in Alberta offer supports via a public guardian. The quality of support provided will be somewhat dependent on the guardian appointed. The public guardian appoints a legal guardian in the absence of family, including extended family. The Office of the Public Guardian seeks the least intrusive or most sensitive solution for the adult in question, and will initially seek out the extended family to take up the needed support. If an appropriate guardian is not available or found, a public guardian will then be appointed to oversee the needed support. As people with disabilities often require immediate aid, a public guardian may play a critical role in assisting with important decision-making issues. This may be necessary to maintain current standards of life in cases that require expertise in the administration of the estate. However, unlike a family member, an appointed guardian will likely not know about all of the challenges facing the individual with disability, especially if the individual has resided with their primary caregiver and was never exposed to external supports.

Financial Supports

Financial supports also exist which are working for some. Alberta offers income support in the form of Assured Income for the Severely Handicapped (AISH). This program is one of the more generous offered by Canadian provinces, but supports end at 65 and AISH is also not indexed to inflation. On the other hand, funds from Persons with Developmental Disabilities (PDD) are not age-limited, but they are based on IQ eligibility.

One concept not available in Alberta is a trust fund that can be set up in the individual's name but is not considered income, and which therefore does not impact income support payments. In Ontario the Henson Trust is one such option for parents, allowing families to place estate assets in the care and control of a trustee to be administered for the benefit of a beneficiary. Inheritances placed in a properly

prepared Absolute Discretionary Trust are not considered the assets of the child and do not affect provincial benefits.

British Columbia also has something similar called a committee ship. A committee ship is an arrangement where the Public Guardian and Trustee, a private individual, or a trust company is granted the authority to manage the affairs of an adult who is incapable of self-management.³

Canada also offers the Registered Disability Savings Plan (RDSP). However, there is a lifetime contribution limit of \$200,000, which limits some families. The majority of eligible families are not currently contributing to an RDSP⁴, with a contribution rate of only 15%. Some families may be unaware of the RDSP, and some may not be able to afford to contribute. Old age security (OAS) is available to those over the age of 65 according to their income level, and most individuals with disability will not be eligible for the Canada Pension Plan (CPP), as many have not worked enough to contribute.

Coalitions Working Toward Quality Sustainable Care

There are several provincial and national coalitions working on various issues related to aging adults with disability. In Ontario, the Ontario Partnership on Aging & Developmental Disabilities (OPADD) is an informal partnership comprised of eight regional committees, with members from a variety of sectors including government, agencies, research facilities and health. The Partnership has been committed to improving the lives of aging people with developmental disabilities for over sixteen years. OPADD attribute much of their success to knowing the strengths and diversity of their communities, and strive to help any of their regions facing challenges to find solutions through the experience and expertise of their membership. OPADD works

³ Trusts in British Columbia: <http://www2.gov.bc.ca/gov/content/governments/policies-for-government/bcea-policy-and-procedure-manual/eligibility/trusts>

⁴ Registered Disability Savings: Why Aren't More Contributing?
<http://www.cbc.ca/news/business/taxes/registered-disability-savings-plans-why-don-t-more-have-them-1.1042380>

on many cross-sector projects, bringing together a variety of partners to improve lives for aging people with developmental disabilities.

Every Canadian Counts (ECC) is a national group seeking potential solutions to address current problems in the delivery of supports and services to Canadians living with disabilities. This group is researching best practices in other developed countries, and hopes to shape the future of how Canada will look after its citizens with disabilities. ECC is currently promoting a national discussion of why Canada can't introduce a national insurance program similar to the ones available in other developed countries. In 2013, Australia launched the National Disability Insurance Scheme (NDIS), a nationwide insurance program for severely disabled Australians. NDIS aims to provide all severely disabled Australians with a uniform program that offers guaranteed lifetime support determined by a needs-based assessment. ECC is hard at work advocating for Canada to adopt a national program that offers the seamless delivery of supports throughout a person's lifetime, without the wait lists that can cause gaps in service. The end goal is a consistent quality of life for people with disabilities.

The PLAN Institute (part of PLAN Canada) is also focused on national policy change and has a number of policy initiatives underway. Their goal is to become the leading influence on caring citizenship in Canada, resulting in improved lives for people with disabilities, their families and their communities.⁵ There may be other coalitions that are working on these issues, but further investigation was limited by time.

A Detailed Support Plan

Many stakeholders suggested that families need to have something on file that summarizes every aspect of their loved one's life, including the medications they require, contact lists that include medical and support workers, sensory diets, behavioural triggers, interests, and many other unique needs that allow for a good quality of life. When parents are in need of a break or unable to support their adult, the designated coordinator or support person could access the "manual" with details of the individual. A manual or an app that enables families to simply "fill in the blanks"

⁵ PLAN Institute: <http://institute.plan.ca/about/vision-mission/>

to create a synopsis of their child or adult to pass on to future caregivers would assist in communicating key information and the unique needs of each individual. This would be especially helpful for those who are non-verbal, low-IQ, or who otherwise have difficulty communicating their needs.

A manual similar to this, entitled *Aging with a Developmental Disability - A Transition Guide for Caregivers*, was written by the Ontario Partnership on Aging and Developmental Disabilities. The manual is available online and offers checklists on topics such as the role of the family and advance care planning.⁶

There may be other agencies that have developed templates for recording important details. What families need, even more than a manual, is to know where to find these resources. Ideally, they should also be able to receive help from a key coordinator to complete and update this information.

Supports for Family

In Calgary, the Sinneave Family Foundation offers the 'Launch into Life' program for families entering into transition at age 18. This in-person seminar offers several evenings of information on transition from adolescence to adulthood, as well as information on housing, the RDSP and the concept of a network. There are numerous other programs and support groups for families in Alberta that provide counseling, stress reduction and education, but most families are either not aware of these resources or do not have the time to participate in these programs. One example is that of parental stress for lifelong care of those with ASD. Extensive research demonstrates that the tremendous stress and lifelong strain families are subject to produces high levels of depression, anxiety and marital distress, but there is no reliable mechanism in place to help families monitor and address these issues with the needed support.

⁶ <http://www.opadd.on.ca/Caregiver/documents/transitionguide-final-sept0105.pdf>

WHAT ARE THE GAPS?

There is no surprise that many gaps still exist. It was frequently noted that families are not planning ahead, and that the system lacks capacity to manage growing needs and increasing numbers. Less well known is the fact that individuals may face yet another support cliff when they move into seniors' services, where financial benefits, aging health issues and housing models may change. The need for mentorship opportunities for both families and individuals, promoting a high-quality, trained workforce, the lack of public awareness and fragmented systems were also noted.

Lack of Planning

The main gap noted by stakeholders was that many parents do not plan ahead until a crisis occurs. Most parents are so focused on day-to-day survival they tend not to plan for the future. The daily stress of caring for their loved one makes it very difficult to take the time to search, plan and coordinate for future needs, and it can be difficult for parents to even think about a time when they are not going to be around. This overwhelming task is often put aside for another day that may never come.

"Many parents are unable to make healthy decisions for their ASD child, as they are under high amounts of stress as a caregiver."

- Stakeholder Quote

Stakeholders who work with families informed us that many families they work with don't have guardianship, a will or an estate plan in place. Upon the passing of primary caregivers, circumstances can change drastically for the family member with a disability. For those who do not plan ahead, questions about who has the legal authority to make decisions that can ensure the sustainability of the individual's quality of life arise. In cases where parents leave suddenly and unexpectedly, the child or adult with a disability could face immediate and basic concerns as simple as the new guardian not knowing what regular medications the individual requires.

In situations where a caregiver passes away and no one is willing or available to settle their affairs, the Office of the Public Guardian and Trustee is available to offer decision-making support if needed, and to assist with the administration of the estate.

However, the appointed guardian may not have any personal knowledge about the individual with a disability, or may lack information about the parent's values or wishes. This can pose a challenge to ensuring the quality of life the child has become accustomed to.

“Families are overwhelmed by where to even start. Eligibility criteria, large amounts of paperwork and knowing what is even available are daunting.”

– Stakeholder Quote

Stakeholders also noted that most families are unaware and unprepared for the financial implications of what happens when they are no longer around. Most caregivers have no idea if their child will have enough funds to cover basic necessities, let alone anything extra to give them a better quality of life. At the most vulnerable point in the dependent child's life, when they have lost their primary caregiver, problems can arise if the parents have not planned ahead. It is possible that the child could lose their AISH funding and be left without sufficient funds to cover their current services, thus severely affecting their quality of life. A parent may bequeath their child with a disability an inheritance over \$100,000, unknowingly disqualifying the child from receiving AISH, and leaving them with funds that may not cover basic care.

“Parents also really need to think about things like what happens if we end up in long term care. How are we going to manage this financially, as well as continue to support our child?”

– Stakeholder Quote

Stakeholders said that a lack of planning, in particular, can have devastating consequences for the population of adults with ASD who currently live with their parents and have never accessed outside supports. These individuals have had no mechanisms to help them adapt to change of any sort. When their caregivers pass away, they may find any transition extremely stressful, as they have never been exposed to people or services outside of their homes. Agencies stated that outreach to educate these families about future planning can be challenging, as they are not in the system and cannot be easily reached.

Many stakeholders felt that what was missing was a navigator or “one-stop shop” for families that would provide them with one place to learn about all aspects of planning: creating a vision, financial planning, housing, individual counseling support, etc. Having this type of navigator in place would help them plan a sustainable quality of life for their dependent children.

“Parents would benefit from advocacy to not only understand the services available for their children, but also to help access the appropriate services to ensure quality care for their disabled child.”

– Stakeholder Quote

Limited System Capacity: The Problem of Wait Lists and Lack of Services

The second main gap that routinely came up in interviews was the problem of huge waiting lists for home placement and support services.

“Families often call in desperation, saying there are not enough available and appropriate adult services or home placement options.”

– Stakeholder Quote

Agencies interviewed stated that once individuals with a disability enter into their system, they are well looked after. The challenge is that there is very little turnover in any of their programs. Unless someone leaves, which is very rare, agencies find it difficult to accommodate new requests, and wait lists can last for years.

However, another stakeholder noted that adults with ASD have to contend not only with general wait lists, but also with additional challenges. For example, it can often be difficult to match an adult with ASD to appropriate roommates or to find a program that can manage their needs. Individuals with ASD tend to have more behavioural and sensory issues than others with neurodevelopmental disabilities. Finding the right placement is even more difficult for these complex individuals, as waiting times can be compounded for even basic needs such as support services.

For high-functioning adults, who are often cut off from services in Alberta at 18 due to IQ score requirements, there are not enough opportunities available to live a good quality of life, whether it is finding affordable housing that meets their desired standard of living or acquiring employment.

*"I need a sense of purpose. I want to be a valued member of a community. There's not enough out there to help someone like me."
– Stakeholder Quote*

Another Cliff To Face: The Transition Over The Age of 65

Many families have heard of what has been called the transition cliff at age 18. This is the move from child to adult service systems, where adult systems are less well-funded and less readily available than those for children, and the full-time daytime supports provided by the school system drop away. However, there is another transition cliff to consider. The third main gap heard about in this consultation was the lack of support for seniors with ASD. Financial scenarios will change at age 65, as well as access to programming. Stakeholders noted concerns about transitioning into yet another environment and housing facility, like aging facilities where staff are not trained in the needs of adults with ASD. Stakeholders felt this population was under-serviced.

Basic care issues were also mentioned as a concern. As adults age, their support needs typically increase due to additional illnesses. Stakeholders noted that, depending on an individual's communication ability, executive functioning levels (which are required for coordination of medical service and oversight of medical needs), and the ability to be a self-advocate, many may not be able to receive the support needed to obtain proper health care.

Stakeholders felt there was a lack of knowledge and research on aging adults with ASD. It is possible that medical conditions may be exacerbated by the individual's disability. Memory loss and dementia, hearing loss, and physical health challenges in someone with a disability may present differently than in a typical population. Very little is known about seniors living with ASD.

"How do you offer these individuals quality of care when people don't even know what they are dealing with?"

– Stakeholder Quote

Mentorship Access

A number of stakeholders noted the lack of mentorship available both for parents and for higher-functioning self-advocates. This concept would offer great hope to others. This gap was noted numerous times, and highlights a significant issue. However, one stakeholder (Gateway) did describe a mentorship program they had created. The program was built around volunteer time from families, using Facebook to host presentations and discussions. This venue gave families the chance to network and tell their stories about what they are doing and what is working. Unfortunately, no other key government individuals or other stakeholders knew anything about this program. These findings underscore an emerging theme in the interviews: there are great ideas and services across Canada, within provinces and even within cities, but parents, individuals, agencies and government workers are not aware of these resources. In this example, the mentorship support suggested by one stakeholder from the general developmental disability field was offered by another stakeholder agency in the autism field.

The Need for a Quality Workforce

Compounding care challenges is a lack of skilled front line workers. In Alberta, there is no formal certification required to work with individuals with a developmental disability. Many front line workers in agencies are not trained specifically on the unique challenges of ASD, and they may be required to perform additional medical care with no formal medical training. Perhaps even more important is finding the right people. There is a need for individuals who are compassionate, caring and go the extra mile to learn about the interests and needs of the individual with ASD; and who continue to create and build a good quality of life for them. Not all providers, even if they are well-trained, are the best people.

*"You need a number of checks and balances so there is always a backup.
After all, this is a human enterprise."
– Stakeholder Quote*

Lack of Public Awareness of the Challenges

As one stakeholder said;

*"I think there is an idealistic view in society that families will take care of their ASD child. That is not always going to be the case, so then what?"
– Stakeholder Quote*

It is most likely that the general public have limited knowledge of the lifelong challenges families and persons living with ASD face. Although this concept was not raised often, it needs to be brought forward as a longstanding gap and a possible reason why there is not strong political will to make significant changes in the world of disability supports. Without significant political pressure, there is less urgency to address this complex, costly, and difficult issue.

Fragmented Systems of Support

One final observation by the writers of this report, not based on stakeholder interviews, was that there exists a serious problem with fragmented and variable supports. A number of times in this consultation process, agencies or individuals that identified a gap were unaware of other agencies or services that may have ideas to fill it. Examples of this were seen in the creation of a network where adult disability service providers were unaware of agencies already doing this work; the need for a mentorship program when another organization was already doing work in this area; and the creation of a support and care plan template that was already available in another province. Across Canada, within provinces, and even within the same city, there may exist resources and supports that parents and individuals are unaware of. Even if they are aware, the effort to seek out, to meet, to co-ordinate, to do the work, and produce a plan is a lot to ask of aging lifelong caregivers of children and adults with ASD. In addition, this fragmentation causes the re-invention of the wheel of work

and added financial strain, both on parents and government; and this is simply a waste of resources.

“Services for adults with developmental disability are fragmented, confusing and complex. Hundreds of agencies exist that make it impossible for families to navigate. Systems are multi-layered, inconsistent, a confusing web of providers, and wait lists lead families and individuals to the brink of disaster.”
– Ontario Report⁷

WHAT INNOVATIVE IDEAS EXIST TO ADDRESS THIS ISSUE?

When asked about innovative ideas to improve the system, stakeholders referenced a wide range of initiatives. The initiatives they mentioned depended on which sector they worked in, and from which perspective they spoke – parent/guardian, individual with ASD, government worker, or agency.

Emerging Technology

The role that technology plays in our world today and will play in the future cannot be ignored. Businesses are emerging that provide solutions where technology may replace the need for some tasks currently performed by front line workers.

“We need to make the lives of both individuals with ASD and their caregivers better. Caregivers cannot possibly provide 24/7 support, especially when they start to age themselves. Technology will free them from some of those responsibilities and likely be more inexpensive than hiring staff.”
– Stakeholder Quote

There are software programs currently being developed using radio frequency identification (RFID) that employ electromagnetic fields to automatically identify and

⁷ Nowhere to Turn. <https://www.ombudsman.on.ca/Resources/Reports/Nowhere-to-Turn.aspx>

track tags attached to objects. The hope is that this technology will be able to support an individual with ASD in their home. This high-tech program will be able to prompt and remind clients to perform tasks and offer some security features. The rollout of this technology should take place in the near future.

Insurance Plan Approach

The Every Canadian Counts coalition is reviewing research on the use of insurance to cover and ensure lifelong quality supports. Government initiatives that establish lifelong supports for individuals and families and use other methods to finance these services could make lives better for persons with disability. In the province of Quebec the government proposed an autonomy insurance plan to address the long-term care needs of an aging population, including those with lifelong disabilities. Autonomy insurance⁸ is an innovative social project intended to address the increasing demands on a system that is complex, inadequate and difficult to access for some. This solution may not benefit those who are already older or elderly, but could provide a long-term solution for future needs.

Mentorship and Visuals of How-To and Toolkits

The need for mentorship was discussed in the “What Are the Gaps?” section. There is a need to match families and individuals who have similar levels of support needs and capacities with those who have had success. One stakeholder suggested a visual presentation that illustrates a series of models to help families see how others have actually developed, implemented and sustained a lifelong quality model. Whether this might exist elsewhere or even in Alberta would require further investigation.

Other stakeholders noted there was a need for a toolkit on how to start your own group living home (or other models). Many agencies stated that families would like to have step-by-step instructions about how to create these supports. Reports found in Appendix B under housing describe many possible models. Another area of concern

⁸ Government of Quebec, Autonomy for All: White Paper on the Creation of Autonomy Insurance.

<http://deslibris.ca/ID/238096>

was the often-forgotten guardians or caregivers who take over from parents. One stakeholder wanted to see a toolkit for people who become legal guardians while initially having minimal knowledge about ASD. This stakeholder believed it was essential to offer more support networks and counseling programs for these individuals.

One-Stop Shop for Families

The concept of one person (a coordinator) or agency that could offer all services and information needed to help families is also worth considering. These accessible "one-stop shop navigators" could help families understand and plan all aspects that encompass a sustainable quality of life for their ASD child. This could include, but would not be limited to: financial planning, service planning, hands-on assistance with filling in and overseeing forms, hand-holding and step-by-step help to create housing, along with many other tasks to oversee quality lifelong support. A new initiative was discovered in Calgary providing a one-stop coordinator, but this service was for anyone in need (with or without a disability), and the providers did not want to advertise the service because they were already overwhelmed.

"Perhaps the government needs to not just change policies, but also put resources into helping families with the planning process. Families can steward responsibly and meet moral and legal obligations in ensuring a sustainable quality of life for their child."

– Stakeholder Quote

Specific Effort to Advocate for Quality Sustainable Housing

Housing-specific initiatives were noted by one key stakeholder who recommended a number of initiatives that need advocacy. Some specific ideas were to:

- Increase the use of social impact bonds
- Allow use of the RDSP as a down-payment for housing

- Create life leases where an individual has the right to occupy a specific space at a fixed rate in perpetuity
- Create a national or provincial housing trust – a trust fund administered by a non-government body that gives people the ability to bequeath a smaller amount of their estate to housing
- Create a rent subsidy program, similar to the one in Quebec
- Enshrine the right of housing into the Canadian Charter of Rights

Related Ideas

The ideas below were offered by stakeholders in this consultation. They are not necessarily new ideas, as advocates have been asking for these changes for some time; however, they are worth repeating. It should be noted that there are likely many other initiatives that have been put forward as areas in need of change.

- Increase research efforts on aging individuals with ASD and their elderly parents. Very little is known about older adults and the issues elderly caregivers face.
- Lobby government to provide more funding and programs for adults in all areas of daily living and increased independence, plus mental health supports, career and volunteer guidance, and social skills.
- Lobby government to change IQ score eligibility so higher-functioning adults can qualify for services.
- Lobby federal government to increase the RDSP contribution to exceed the current \$200,000 amount. The government should also continue to ensure that RDSP contributions are not considered assets, and so do not impact income support program amounts.
- Lobby government to increase exemptions in different areas, such as allowing families to put funds into an annuity.
- Lobby the government to create a program that incentivizes parents to keep their adults with ASD at home. Compensate parents and encourage families to continue looking after their adult in their own homes, if they wish to do so. However, this can only be viable with added (and still unavailable) supports like out-of-home respite

programs, easily accessible in-home respite, and additional services that help aging parents.

CONCLUSION

The ASA board set out to understand what programs and supports currently exist to take care of our kids when families can no longer do so. Although good examples of quality, sustainable life exist, they are not easily accessible, may be difficult to duplicate, and are not meeting the growing demand.

For the moment, the best way forward would be for families to have aspects of a number of the “things that are working” in place. For example, in the ideal situation a family would contribute financially to an RDSP on a regular basis. They would obtain a quality housing situation with a quality service provider that involves parents in decisions. There would be a clear support plan template in place and an identified network of support people. They would do all this while living in a province where a trust could be set up that would not impact income support payments. This would likely be, at this time, one of the best scenarios possible. Clearly, this is difficult to create and requires extensive knowledge, capacity, financial ability and time from the aging parent. For many, this is unrealistic.

Autism spectrum disorders present an especially challenging situation, as individuals have a wide range of ability, layered with possible medical and mental health challenges, as well as sensory and behavioural issues. All of these factors are then combined with aging and tired families with variable mental, medical, and financial capacity. The system is fragmented, and agencies, families and individuals everywhere are reinventing the work that may already be done elsewhere.

Families often fall between the system's cracks, and many come face-to-face with this when a crisis arises and there is an absence of needed supports. This may be especially true for families that lack capacity to take action early on for their loved ones. Even for families who have a high level of capacity, the lack of direction and the time needed to seek out the required supports to create this life leave families overwhelmed and unsure of how to proceed.

Many organizations are trying hard to answer the question the ASA board set out to understand. There is progress being made, and each day new and hopeful innovations and connections are being made throughout Canada.

“You have to keep trying and give families a sense of hope. Hope is the one thing that helps families continue on their journey.”

– Stakeholder Quote

This project has revealed important resources and programs. This report attempts to convey a sense of hope that positive movement is occurring, while at the same time highlighting a sense of urgency that families are struggling and a better way forward must be created.

APPENDIX A: STAKEHOLDERS INTERVIEWED

Thanks to the following organizations, agencies, families and guardians, self-advocates and government branches that provided information. A total of 34 stakeholders were interviewed over 3 months.

Agency	Stakeholder Interviewed
<i>ARNIKA</i>	Dr. Jennifer Hibbard, Clinical Medical Director
<i>Autism Awareness Centre, Inc.</i>	Maureen Benny, Director
<i>Autism Calgary</i>	Lyndon Parakin, Executive Director Maria Vial, Family Support Coordinator
<i>Autism Edmonton</i>	Carole Anne Patenaude, Executive Director Matthew Kay, Adult Support Coordinator
<i>Autism Speaks Canada</i>	Esther Ree, National Program Director
<i>Autism Speaks USA</i>	Leslie Long, Vice President Adult Services
<i>Brockville & District Association For Community Living</i>	Denise Wright, Executive Director Laurelle Avery, Family Support and Housing Resource Coordinator
<i>Community Living Victoria</i>	Julie Hickey, Program Manager
<i>Gateway Association</i>	Bobbie Killian, Director of Family Support
<i>Inclusion Alberta</i>	Bruce Uditsky, CEO
<i>L'Arche Association of Calgary</i>	Garth Reesor, Executive Director
<i>March of Dimes</i>	Brent Page, National Manager Community Integration

Ontario Partnership on Aging & Developmental Disabilities Sandy Stemp, Lead for OPADD and COO, Reena

Options Elaine Yost, President/Director

Plan Institute Rebecca Pauls, Director

PLAN Lethbridge Dave Lawson, Executive Director, Lethbridge Association for Community Living

Sinneave Family Foundation John Seigner, Manager, Resource Centre/Director, of Housing

Supported Lifestyles Heather Porter, Residential Director

URSA Pam McGladdery, Executive Director

Vecova Debi Lefavre, Director of Living Support Services

Parent/Legal Guardian

Brenda McInnis Parent

Marli Robertson Parent

Teresa Scarlett Legal guardian to a family member with ASD

Private Sector

Disability Advocates Annie, VanderLeek, Disability Advocate

VanderLeek Law Gordon, VanderLeek, Barrister & Solicitor

Self-Advocates

Michael Frost Adult with high functioning autism

Vincent Gauthier

Self-Advocate

An additional three agencies, three government branches and a research institute also participated in interviews but requested not to be named.

APPENDIX B: RESOURCES FROM INTERVIEWS

Alberta Supports

Alberta Supports is making it easier for Albertans to find information and access more than 120 social-based supports offered by Human Services and Health online, by telephone or in person. Check out albertasupports.ca for more information.

Assured Income for the Severely Handicapped (AISH) Program Policy

AISH provides assistance to adult Albertans with permanent disabilities that substantially limit their ability to earn a living. The following website will give families a complete overview of the program, including eligibility and income implications.

<http://www.humanservices.alberta.ca/AWonline/AISH/7180.html>

Autism Awareness Centre Inc.

Autism Awareness Centre Inc. is a national conference and training provider and has an online bookstore. The conferences and trainings give an in-depth look at the cutting-edge resources available, and tips on how to use them. The online bookstore is a robust collection of hand-picked books and resources on autism and related disabilities. AACI offers information, articles, help in your area, links and global resources in the autism and related disability fields.

<https://autismawarenesscentre.com/>

Autism Calgary's Adult Life with Autism Spectrum Disorder

This self-help guide assists families and adults living with ASD in planning for a meaningful adult life.

<http://www.autismcalgary.com/wp-content/AdultGuideOrderForm.pdf>

Autism Edmonton's Next Steps: Guide to Autism Resources

This online guide has a section for adults (18 years and up) that offers families and adults living with ASD the ability to navigate options for services.

<https://www.autismedmonton.org/next-steps>

Autism Speaks Canada Toolkits

Autism Speaks Canada offers families and individuals with ASD a variety of online toolkits they can access for free. Toolkits help demystify topics such as employment, financial planning, housing and community living.

<http://www.autismspeaks.ca/research-and-services/resources/tool-kits/>

Every Canadian Counts

<http://everycanadiancounts.com/about/>

Launch Into Life

The Ability Hub (Calgary), A Resource Guide for Parents of Adolescents with ASD.

<https://www.theabilityhub.org/Initiatives/launch>

Microboards

<http://www.velacanada.org/>

Office of the Public Guardian and Trustee

When a caregiver passes away and no one is willing or available to settle their affairs, the Office of the Public Guardian and Trustee is available to offer decision-making support, if needed, and to assist with the administration of the estate.

<http://www.humanservices.alberta.ca/guardianship-trusteeship.html>

Ontario Partnership on Aging & Developmental Disabilities (OPADD)

<http://www.opadd.on.ca/>

Persons with Developmental Disabilities (PDD)

This website will help families and individuals with ASD navigate the world of PDD funding and services. The question and answer format is helpful for finding the exact information sought..

<http://www.humanservices.alberta.ca/disability-services/pdd-calgary-publications-learn-about-pdd.html#01>

Planned Lifetime Advocacy Network (PLAN)

<http://theroadahead.ca/>

PLAN Institute

<http://institute.plan.ca>

Safe and Secure: 2015 Expanded RDSP Edition (BC)

This book, authored by Al Etmanski with Jack Collins and Vickie Cammack, offers families a step-by-step guide to creating a plan for the future.

<https://store.planinstitute.ca/collections/books>

Seniors Programs and Services

Once an adult with a disability turns 65 years of age, they must transition from AISH to Seniors Programs and Services. The following information guide offers descriptions of all the Government of Alberta financial assistance programs for seniors.

<http://www.seniors-housing.alberta.ca/documents/Seniors-ProgramsServicesGuide.pdf>

Sinneave Foundation/Ability Hub Visual Resources

This organization offers video and multimedia resources that provide insight into the different areas of vocational programs. It even includes a visual synopsis that highlights the experiences of parents and individuals with ASD as they have transitioned from adolescence to adulthood.

<https://www.theabilityhub.org/resources/video-and-multimedia>

Housing-Related Resources

Note: This is a partial list of what exists.

Autism Speaks USA

The Autism Speaks House to Home Prize Competition asked people to submit creative ideas to develop alternative housing and support services for the growing number of adults with ASD. Over 250 entries from 63 countries were reviewed in categories like 24/7, daily and weekly supports. For a complete list of winners and detailed descriptions of their models, visit

<https://www.autismspeaks.org/HouseToHomePrize>.

Camphill Association of North America

An international movement of intentional communities designed to meet the unique needs of individuals with developmental disabilities through a combination of community life, the arts and work on the land. There are over 100 Camphill communities worldwide and 11 communities throughout the United States and Canada (British Columbia and Ontario).

<http://www.camphill.org/>

Community Involvement Legacy Homes

A nonprofit charitable housing corporation that provides secure housing in the municipalities of Leeds and Granville, Ontario. CILH offers people with intellectual disabilities tenure through a lease agreement.

<http://www.cilh.ca>

Farmsteads

Popular in the United States, British Columbia and Ontario, farmstead models incorporate a licensed residence with a fully operational working farm. Individuals with developmental disabilities participate in the day-to-day operation of the farm while getting the support services they require.

<http://www.friendshipcircle.org/blog/2013/03/04/15-farm-ranch-communities-for-individuals-with-special-needs/>

<http://www.bloomingacres.com/>

Group Living

Individuals with disabilities may share a home with one or more peer roommates and receive support from trained staff in any area of daily living. The specific needs of each individual are determined, and staff come into the home and are available to provide support up to 24 hours a day.

<http://vecova.ca/services/areas-of-service/community-living/>

<http://optionsrehab.org/>

Intentional Communities - Villages

In places like Florida in the United States, intentional communities offer individuals with a developmental disability an option for affordable housing that brings together community supports and services, offering a fully inclusive environment. These communities can be privately funded or be a blending of public and private funds.

<http://noahsarkflorida.org/>

L'Arche

An international organization that offers individuals with disabilities a model of care with a spiritual context. In Calgary, L'Arche operates five homes, a supported independent living program and a day program. L'Arche homes pair people with and without disabilities who want to share a life together. This model of live-in staff is designed to create a sense of community and belonging.

<http://www.larchecalgary.org/>

Life Leases

A life lease is a legal agreement where an individual purchases the right to occupy a home for life or a fixed term or until they are no longer capable of living in that unit. It can often be a model for affordable housing that offers individuals security of tenure.

<http://www.cplea.ca/wp-content/uploads/2015/12/LifeLeases.pdf>

Reena Community Residence

This unique residence opened in 2012 and operates as an intentional community integrating home, supports, programs and recreational activities to assist adults and seniors with a diverse range of disabilities. Located on the Joseph and Wolf Lebovic Jewish Community Campus in Vaughan, Ontario, this model has worked so well that similar communities are being considered in other regions.

<http://www.reena.org/about/reena-community-residence/>

Supported Roommates

Supported roommates share their principal residence with an individual with a disability. The objective of this model is to provide long-term support in all the areas the individual with a disability may require in daily life. The Supportive Roommate

model of service provides the unique opportunity for individuals with a disability to receive residential supports from an all-inclusive consistent family base.

<http://www.supportedlifestyles.com/services/residential-services.html>