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## THE VALUE OF CAREGIVER TIME: COSTS OF SUPPORT AND CARE FOR INDIVIDUALS LIVING WITH AUTISM SPECTRUM DISORDER

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### SUMMARY

When a child is diagnosed with autism spectrum disorder, the significance of the impact that diagnosis can have on his or her family's life is incalculable, except in one respect: cost. If that child is severely impacted and requires constant and lifelong supports, then the value of caregiver time required to support that individual is approximately \$5.5 million higher than that for someone without autism. An autism diagnosis of a high-needs child at age two represents the equivalent of telling the family that they must make an immediate lump-sum investment on that day of \$1.6 million, invested at a five-per-cent return, to pay for the lifetime costs of care and support their loved one will require. And that amount does not even account for added professional services, such as speech therapists, psychologists, and occupational therapists, or additional out-of-pocket expenses that may be required, such as special equipment or diets.

Autism is the most common neurological condition diagnosed in children and it is now estimated that one in 88 children will be diagnosed with autism spectrum disorders. Yet, across Canada, there are significant gaps in the publicly provided support system, leaving the cost burden to be picked up by families. In the case of those individuals requiring constant support, 24 hours a day, every day, the cost of hiring caregivers alone would require an annual income of \$200,000 – before a family even begins to pay for shelter, clothing, groceries and other basic necessities. Already families with severe high-needs children are more likely to experience lower income than they might otherwise, due to the extra care commitment their loved one requires. Only a very few families will have the means to afford to pay for total care. So, in most cases, the responsibility for care falls largely, if not entirely, on the family, or in a worst-case scenario, the autistic individual is left with inadequate care.

Autism is an expensive condition and governments may underestimate the full cost of community-based supports needed for the vast range of unique needs of those living with autism. A scan of provincial programs finds a patchwork of unequal and incomplete supports for individuals living with autism spectrum disorders. Gaps are particularly evident once individuals leave the public school system, where they are at least provided with some form of day support. Sufficient adult day supports, evening and night supports, quality group homes, the availability of properly trained caregivers and respite services, recreational activities, post-secondary opportunities and employment supports all suffer varying levels of inadequacy across the country.

As autism becomes increasingly prevalent, continuing to rely largely on family supports where community services are fragmented or unavailable is not a sustainable approach. Canadian policy-makers will need to consider the costs of a growing and aging population of individuals living with autism who need a range of supports so that adequate quality of care and a decent quality of life are enjoyed by many who remain some of this country's most vulnerable citizens.

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## INTRODUCTION

Autism spectrum disorder (ASD) is a lifelong neurological condition estimated to affect as many as one in 88 children.<sup>1</sup> It is now the most common neurological disorder affecting children and one of the most common developmental disabilities.<sup>2</sup> Many individuals living with ASD will need some level of support over their entire lives. In cases where adolescents and adults with severe autism are placed into long-term care or other supported housing arrangements the annual cost of housing, which includes caregiver time, can be \$400 per day, amounting to approximately \$150,000 a year.<sup>3</sup> Few Canadian families generate sufficient income to cover such high costs of support. Even where families with ASD dependents have income to pay for some of the required care needed, they face challenges finding available and qualified caregivers.<sup>4</sup> Unfortunately, as families of ASD dependents age or become financially unable to care, it is not obvious how their adult with ASD will be supported other than with the burden falling on the state.

In this report we hope to contribute a Canadian perspective on costs of care and to highlight the heterogeneity of the spectrum of care costs required to meet the spectrum of support needs. We estimate the lifespan value of caregiver time alone to support a severely impacted individual with ASD to be approximately \$5.5 million above the costs of a neurotypical individual. Costs will start at this amount for any individual needing 24-hour support seven days a week, and will decrease with increasing independence. This amount represents the equivalent of telling a family at the age of their child's diagnosis — which is, for many, at the age of two — that they need to make a lump-sum investment on that day of \$1.6 million (invested at five per cent) to pay for the lifetime costs of care and support their loved one will need. These costs are in addition to the costs of added professionals, such as speech therapists, occupational therapists, and psychologists, and other additional out-of-pocket expenses, such as special equipment or diets. These lifetime costs of care are much higher than what the current cost-research findings indicate, where lifetime autism costs range from \$1.2 million to \$4.7 million for “an average” or “typical” person on the autism spectrum.<sup>5</sup>

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<sup>1</sup> Centers for Disease Control and Prevention (CDC): <http://www.cdc.gov/ncbddd/autism/data.html>.

<sup>2</sup> Autism Society Canada website, ASD Research, “Prevalence,” [http://www.autismsocietycanada.ca/index.php?option=com\\_content&view=article&id=55&Itemid=85&lang=en](http://www.autismsocietycanada.ca/index.php?option=com_content&view=article&id=55&Itemid=85&lang=en).

<sup>3</sup> Laurie Monsebraaten, “Frantic Parents Search for Housing for Severely Autistic Son,” *Toronto Star*, Sept. 22, 2012, <http://www.thestar.com/news/gta/article/1260802--frantic-parents-search-for-housing-for-severely-autistic-son>. This Ontario report told of the frantic search by parents for housing for their severely autistic son, aged 19, after emergency funding for his group-home placement (in the amount of \$400 a day) ran out. The family had already spent \$750,000 thus far to care for him. They were depleted of resources and could no longer cope. Service representatives stated that he was not the only one, and that there was no flexibility in communities to create the response that people need. The need exceeded the funds..

<sup>4</sup> Eric Collins, “Latest scalding ‘not acceptable,’ says associate minister,” *Calgary Herald*, March 13, 2013, <http://www.calgaryherald.com/health/Calls+grow+better+training+care+homes+people+with+disabilities/7725229/story.html>. In Alberta, staff shortages and inadequate training were thought to contribute to the poor care in government-operated care homes.

<sup>5</sup> D. Amendah et al., “The Economic costs of Autism: A Review,” in *Autism Spectrum Disorders*, ed. D. G. Amaral and D.H. Geschwind, (New York: Oxford University Press, 2009), 1347-1360.

The process to ensure a fully realized life must ensure a commitment to provide resources that enable a good life for everyone across the spectrum.<sup>6</sup> Autism is a complex and expensive condition and governments in most jurisdictions are struggling with how to provide resources and manage the increasing demands on service systems that provide long-term care and supports for those with disability. The presence of inadequate services could reflect the problem that governments are underestimating the full cost of community-based supports for the vast range of unique needs of those living with a neurodevelopmental spectrum disorder, such as autism.

For example, the Alberta government recently closed the last institution to house individuals with disabilities. This was inevitable, but shortly after that came the news of changes to the delivery of services for those who fall under support for the Persons with Developmental Disabilities (PDD) program. Individuals and families worried that the re-allocation of community-access funding would leave some individuals isolated and increasingly more dependent on family.<sup>7</sup> The government's intention was not to cut services, but to redesign the current delivery system for adults with developmental disabilities to expand services to those who need help but do not currently qualify.<sup>8</sup> Yet, the end of institutional care combined with the movement of funding away from community-support services created serious concerns for many. The complete transition of disability services into the community in the face of a lack of quality housing, the lack of a range of respite options, support-staff shortages, limited quality day programs and employment opportunities for adults living with ASD is concerning.

In Canada the public health response to ASD must begin to consider not only the direction and course of funds for ASD research but also how these funds are distributed, given the diversity of needs for individuals living with ASD.<sup>9</sup> Individuals who are unable to reach full independence will require supports and these supports must be paid for in some way. How the support is financed currently comes down to several key issues: What is a reasonable amount for governments to contribute? What is a reasonable amount for families to provide, in terms of their own income, to either pay for outside caregivers versus the opportunity costs of time for caregivers within the household? How much is a family willing to take a chance that an external-care situation will be capable of managing the needs of the individual and ultimately what is the right balance of the care and support contribution in Canadian society that ensures quality of life for individuals and families across the spectrum and over the lifespan?

Solutions to these issues will likely be innovative and will not reflect the status quo. Innovative ideas do exist. One example of innovation that we review in the discussion of issues comes from the province of Quebec, where a unique insurance plan is emerging that will seek to ensure the availability of lifelong supports for all adults with disability who need help.

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<sup>6</sup> Bruce Uditsky, "Closure of Michener Centre was Inevitable," *Edmonton Journal*, April 1, 2013.

<sup>7</sup> Jamie Komarnicki, "Cuts Create Fears for Disabled," *Calgary Herald*, March 29, 2013.

<sup>8</sup> Alberta Government Human Services Website, "Persons with Developmental Disabilities (PDD)," <http://humanservices.alberta.ca/disability-services/pdd.html>.

<sup>9</sup> T. M. Krahn and A. Fenton, "Funding priorities: Autism and the need for a more balanced research agenda in Canada," *Public Health Ethics* 5, 3 (2012): 296-310.

## Project Aim and Method

As part of a greater understanding of the well-being of persons on the spectrum and of their families, we need better information on the support needs and costs for individuals living with ASD. To that end, the aim of this report is threefold. First, we perform an accounting exercise to determine the total value of caregiver time required to meet the full needs of a person with ASD. This is a calculation of caregiver time and costs above the needs of a neurotypical individual. Second, we highlight the range of ways in which these supportive care needs can be paid for. Third, we review provincial policies and supports available to persons with ASD for meeting their care needs over the life course to infer how much of their needs are currently being met.<sup>10</sup>

Our focus in this report is the care needs of individuals on the spectrum and not specifically on the burden on families for providing that care, for which there is a larger body of literature. As we explain, we consider the burden of caregiving as an issue of how care services are provided or paid for rather than about the quantification of the value of needs. Stress and diminished health of family caregivers are often part of the price of meeting needs. The literature on the costs of autism have as well focused on expenditures of care, including foregone earnings of family caregivers, which has likely led to an underestimation of the full cost of meeting all needs. For example, care not provided cannot be accounted for using expenditure-based approaches and care not provided represents a high price borne by the person on the spectrum.

The following method was used to achieve the aim of the project:

- 1) We reviewed the literature by searching research databases and Google Scholar for peer-reviewed research regarding ASD support-care needs and costs, specifically in the area of adolescence and adulthood.
- 2) We created a lifespan “needs map” for three hypothetical individuals with ASD that describes needs that are above those of a neurotypical individual, over the life stages from adolescence to adulthood.
- 3) We estimated the costs of care using the replacement value for caregiver time required to meet the needs.
- 4) We searched the Internet for provincial government policies and programs that address the dimensions of the needs map.
- 5) We estimated the dollar amounts available through existing programs and identified the value of the gaps.
- 6) We identified overall findings, promising policies and programs as well as policy or program gaps.

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<sup>10</sup> This project report is one in a series of reports from the lifespan policy initiative. Policies across the Provinces from a Lifespan Perspective is a project intended to inventory provincial policies and programs that exist to support individuals living with autism spectrum disorder and their families. The purpose of the inventory is to assess what is being done well, what is being missed, and where the most promising or pressing program needs are. Several areas of interest were identified as areas for policy review including: transportation, accommodation, caregiver, employment, health, education, recreation and income.

The terms support, care and supportive care will be used interchangeably throughout this report to refer to the continuum of hands-on care and support needed for individuals living with ASD. A continuum of care in the traditional sense of care is often used to describe the situation where everything is done for a person. A continuum of support refers to the type of support that encourages an individual with ASD to learn, with the ultimate goal of maximum independence. For all on the spectrum, regardless of their level of functioning, the goal should be to move towards their full potential for independence.<sup>11</sup> Still, it must be acknowledged that there will be some individuals who will likely always require a degree of hands-on care for their entire life. For this reason the words “care” and “support” will be used interchangeably to refer to the continuum of supportive care.

This report should not be interpreted as intending to “farm out” all tasks needed to support individuals with ASD. Many individuals are supported by parents, siblings and extended family out of love and respect, and these caregivers do not wish to hand over or “farm out” the care. Many do not consider the care to be a burden, and they are simply looking for the best possible quality of life for their loved one. Still, many families are burdened under the tremendous demands of lifelong caregiving to the point of exhaustion and ill health. The intention of this project is not to minimize the meaning of care by measuring, quantifying or costing services, but to highlight the type and level of supportive care needed and the related costs. Many of these issues are shared by others who struggle with neurodevelopmental conditions, and although we use the lens of ASD to examine these issues, we hope that findings will benefit all who live with similar challenges.

## LITERATURE REVIEW

To date, the peer-reviewed published literature on care costs is limited as far as the value of caregiver time, the type of supportive care needed, and costs of that care for the individual. A much larger body of literature focuses on the caregivers themselves in regards to stress, fatigue, poor health and burden. The resulting message from these numerous studies is that lifelong caregiving is very stressful and, in the context of unprepared support systems, is not sustainable.<sup>12</sup> As we discuss later, these impacts of caregiving on the caregiver are part of the price of care giving rather than the value of meeting the needs.

### What Supports are Needed?

What are the supports needed for those living with ASD? In a survey of 143 American Midwest families caring for an adult with autism, the majority of adults (58 per cent) needed help with activities of daily living (toileting, bathing, dressing). Even more (84 per cent) required help with auxiliary daily living skills, such as bill paying, cooking and cleaning. This study also found a lack of available support for caregivers and limited opportunities for the family member in the areas of socialization, employment and residential living, especially for those most severely affected.<sup>13</sup>

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<sup>11</sup> Adapted from: Maureen Bennie, “Housing for Adults: Living a Good Life, a Model for Success,” Autism Awareness Centre, <http://www.autismawarenesscentre.com/maureens-blog/315-living-the-good-life-a-model-for-success>.

<sup>12</sup> M. Rowbotham, M. Cuskelly and A. Carroll, “Sustainable care giving? Demands upon and resources of female carers of adults with intellectual disability,” *Journal of Women and Aging* 23 (2011): 129-148.

<sup>13</sup> J. E. Graetz, “Autism grows up: opportunities for adult with autism,” *Disability and Society* 25, 1 (2010): 33-47.

In an Ontario survey of 480 individuals with ASD, ages 16 to 66, more than 50 per cent needed help with tasks of daily living, such as household chores, attending appointments, arranging appointments, managing finances, and more than 60 per cent of the sample needed help finding and using services. Of the sample, 30 per cent needed help with the very basics of personal hygiene. The largest group of subjects (50.8 per cent) was considered higher functioning.<sup>14</sup>

Executive-functioning or higher-order cognitive processes, such as planning, strategy formation, and flexibility, are skills found to be impaired for many people living with ASD. These executive-functioning deficits likely follow a consistent trajectory into adulthood.<sup>15</sup> Individuals with ASD who lack these basic skills of planning and co-ordinating will need support in all areas where these tasks are needed. For example, the task of advocacy was shown to be an important role in assisting people with intellectual disability to allow access to health care, along with other sectors needed to address psychosocial needs. Parents and support workers played an important role in helping adults with advocacy.<sup>16</sup>

Supervision and vigilance is needed for some on the spectrum. In a study of mothers of boys with autism, the mothers characterized the type of care as “vigilance,” because their children needed ongoing and intense focus in self-care, leisure and social activities to prevent frustration and behavioural meltdowns.<sup>17</sup> In another study, the occurrence of escape and running behaviours, referred to as elopement, was found to be a problem. In this study, 1,218 children and adolescents with ASD were paired with normally developing siblings without ASD. In total, 49 per cent of families reported at least one attempt of the ASD individual to elope once after age four and of those who eloped, 24 per cent were in danger of drowning and 65 per cent were in danger of traffic, while none of the families reported elopement for the normal siblings. Elopement risk was associated with severity. Elopement increased occurrences of injury and death and placed a major burden on families.<sup>18</sup> Similar studies on elopement, wandering or running were not found for adults and so it is unknown if this remains a problem into adulthood.

A report from a Danish study showed higher rates of death for adult individuals with variants of ASD. In this study, over a 30-year period, the mortality rate of individuals with ASD was nearly twice that of the general population. A number of the deaths were associated with the presence of epilepsy and the authors recommend better management of the complex relationships between ASD and physical illness to prevent avoidable deaths.<sup>19</sup> It is clear from past research that a variety of supports are needed for many living with ASD over their lifespan, not only to survive, but also to cope with the demands of everyday life.

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<sup>14</sup> K. P. Stoddart et al., “Diversity in Ontario’s Youth and Adults with Autism Spectrum Disorders: Complex Needs in Unprepared Systems” (Toronto: The Redpath Centre, 2013).

<sup>15</sup> J. Bramham et al., “Executive functioning differences between adults with attention deficit hyperactivity disorder and autistic spectrum disorder in initiative, planning and strategy formation,” *Autism* 13, 3 (2009): 245-264; Stoddart et al., “Diversity in Ontario’s.”

<sup>16</sup> C.E. Brolan et al., “Health advocacy: a vital step in attaining human rights for adults with intellectual disability,” *Journal of Intellectual Disability Research* 56, 11 (2012): 1087-1097.

<sup>17</sup> E. Larson, “Ever vigilant: maternal support of participation in daily life for boys with autism,” *Physical and Occupational Therapy in Pediatrics* 30, 1 (February 2010): 16-27.

<sup>18</sup> C. Anderson et al., “Occurrence of family impact of elopement in children with Autism Spectrum Disorders,” *Pediatrics* 130, 5 (2012): 870-877.

<sup>19</sup> S. E. Mouridsen et al., “Mortality and causes of death in autism spectrum disorders,” *Autism* 12, 4 (2008): 403-414.

## What are the Impacts of Co-Morbid Physical/Mental Health Conditions and Severe Behaviours?

Co-morbid health conditions are common amongst those living with ASD. Kohane et al.<sup>20</sup> found that individuals with autism face added physical and mental health challenges. In their study of three hospital settings, 1,400 individuals living with ASD up to age 35 were compared to the normal hospital population. Young adults with ASD suffered significantly higher rates of co-morbid conditions such as epilepsy, schizophrenia, sleep disorders and bowel conditions than did the overall hospital population. Some conditions were found to increase with age.

High levels of mental health conditions exist. In the Ontario study, 45 per cent of 480 individuals with ASD reported anxiety and 27.9 per cent reported depression. The majority of these study subjects were individuals with ASD not considered intellectually impaired.<sup>21</sup> A review of research of anxiety in children and adolescents with Pervasive Developmental Disorder without retardation led authors to the conclusion that 42 per cent of individuals with higher-functioning autism and Asperger syndrome experience anxiety. Anxiety is a major problem for some individuals on the spectrum.<sup>22</sup>

Behaviours can also present lifelong challenges; for some people living with ASD, and problem behaviours can occur at high rates and severity. Behaviours can impact anyone on the spectrum, and the type of behaviour and consequences may vary. In one study, the presence of abnormal repetitive behaviour and the level of behaviour severity were higher for individuals with intellectual disability living with ASD in comparison to those without. In this group, the presence of compulsions, stereotypy, and self-injury occurred more often and occurrences were more severe.<sup>23</sup> Adults with severe ASD behaviours continue to demonstrate severe behaviours over their lifespan, and the severity was greater in ASD than other disabled individuals matched for cognitive disability. Lifelong behavioural planning would be beneficial for this group of adults.<sup>24</sup> Challenging behaviours and mental health issues combined with intellectual disability are a factor in increased family burden. Families with an individual who had these complicating issues felt more stress, especially where they found a lack of services, complexity of systems, and a lack of professional support to help them learn skills to maintain the involvement of their relative.<sup>25</sup>

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<sup>20</sup> I. S. Kohane et al., "The co-morbidity burden of children and young adults with autism spectrum disorders," *PLoS ONE* 7, 4:e33224 (2012).

<sup>21</sup> Stoddart et al., "Diversity in Ontario's."

<sup>22</sup> M. Soussana et al., "Anxiety in children and adolescents with pervasive developmental disorder without mental retardation: a review of literature," *Encephale* 38, 1 (February, 2012): 16-24.

<sup>23</sup> J. W. Bodfish et al., "Varieties of repetitive behaviour in autism: Comparisons to mental retardation," *Journal of Autism and Developmental Disorders* 30, 3 (2000): 237-243.

<sup>24</sup> J. L. Matson and T. T. Rivet, "Characteristics of challenging behaviours in adults with autistic disorder, PDD-NOS, and intellectual disability," *Journal of Intellectual and Developmental Disability* 33, 4 (December 2008): 323-329.

<sup>25</sup> N. James, "The formal support experiences of family carers of people with an intellectual disability who also display challenging behaviour and/or mental health issues: What do carers say?" *Journal of Intellectual Disabilities* 17, 1 (2013): 6-23.

Higher-functioning individuals can also experience severe behaviour. The unique characteristics of Asperger syndrome — intense narrow interests coupled with lack of social awareness and lack of social constraints on behaviour — can result in increased criminal acts.<sup>26</sup> To better understand the higher rates of police engagements, Newman and Mohammad<sup>27</sup> found in a review of literature that undiagnosed psychiatric disorders in individuals with Asperger syndrome played a role in those involved in the occurrence of violent crimes. The authors recommended better diagnosis and treatment of psychiatric disorders for those with Asperger syndrome.

Examples of the impact and consequences of problem behaviours are also found for seniors living with dementia. Severe abusive and violent behaviours can occur in cases of dementia and have a significant impact on caregivers. This was noted in a situation where a caregiver spouse experienced aggression from her husband with dementia. Fearing for her life she called 911, which resulted in police involvement an inappropriate jail sentence for the ill husband, and ultimately, out-of-home care.<sup>28</sup>

Unmanaged sensory challenges can create sensory-related behaviours and unique support needs. It is estimated that over 80 per cent of individuals with ASD demonstrate behaviours related to sensory issues such as self-stimulation (rocking or spinning), avoidance behaviours (hands over ears in response to noise), sensory seeking (chewing, twirling) and tuning-out behaviours (not responding to their name or environment).<sup>29</sup> A meta-analysis of 14 studies of children with ASD showed a higher frequency of sensory-related behaviours than in typically developing children.<sup>30</sup> In a qualitative study, sensory issues were one factor that limited family participation in leisure, work and family activities. Parents used specific strategies to manage in light of the sensory-related behaviours.<sup>31</sup>

In summary, the research findings indicate that individuals across the spectrum suffer from higher rates of mental health problems such as anxiety, depression and schizophrenia, and are more prone than neurotypicals to develop medical conditions such as epilepsy and bowel disorders. Severe challenging behaviours and sensory issues can exist regardless of where the individual is on the spectrum. Unfortunately, there remains a lack of research on the heterogeneity of people on the autism spectrum and the presence of co-morbid conditions; in particular how these conditions impact service needs.<sup>32</sup> The impacts of these specific and challenging issues on support time and costs are unclear.

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<sup>26</sup> B. G. Haskins and J. A. Silva, "Asperger's disorder and criminal behaviour: Forensic-psychiatric considerations," *Journal of American Academy of Psychiatry and the Law* 34, 3 (September 2006): 374-384.

<sup>27</sup> S. Newman and G. Mohammad, "Violent crime in Asperger syndrome: The role of psychiatric comorbidity," *Journal of Autism and Developmental Disorders* 38, 10 (2008): 1848-1852.

<sup>28</sup> Linda Nguyen, "Making the Call," *Calgary Herald*, July 26, 2012, <http://www2.canada.com/calgaryherald/news/reallife/story.html?id=ab2b0479-a618-4cea-8eb6-cd9bc1881fb7>.

<sup>29</sup> S. J. Rogers, S. Hepburn and E. Wehner, "Parent reports of sensory symptoms in toddlers with autism and those with other developmental disorders," *Journal of Autism and Developmental Disorders* 33, 6 (December 2003): 631-42.

<sup>30</sup> M. Liss et al., "Sensory and attention abnormalities in autism spectrum disorders," *Autism* 10 (2006): 155-172.

<sup>31</sup> R. C. Schaaf et al., "The everyday routines of families of children with autism," *Autism* 15, 3 (2011): 373-389.

<sup>32</sup> P. T. Shattuck et al., "Services for adults with an Autism Spectrum Disorder," *Canadian Journal of Psychiatry* 57, 5 (2012): 284-291.



## What is Known About Adult Interventions?

Very little is known about effective intervention programs for adults.<sup>33</sup> In a systematic review of research on interventions for adolescents and adults, many studies were found to be of poor quality and lacking in scientific rigor. Service research does not reflect the heterogeneity of impairment, the demographic, or the range of services needed to help adults function with purpose in their communities. Reviews of research in the areas of behavioural interventions, educational interventions, adaptive life skills, vocational, medical and allied health interventions led the authors to conclude that it is unknown what type of interventions work for whom on the spectrum.<sup>34</sup>

## What is Known About Adult Outcomes?

Not only are there gaps in adult best-practice, there is also uncertainty about how individuals with ASD do over their lifespan. Most recent reviews by Howlin and Moss<sup>35</sup> found that research into outcomes for adults was limited. Some studies show that autism-symptom severity may reduce over time,<sup>36</sup> but it is evident that outcomes are mixed.<sup>37</sup> In a systematic review of adult-outcome literature, the authors conclude that outcomes are variable: some individuals improve markedly while others deteriorate.<sup>38</sup> For example, one study of individuals with intellectual disability (ID) showed worse outcomes for those with IQ less than 50; few lived alone, had close friends, or permanent employment. Those with higher IQ had significantly better outcomes; however of those with IQ in the normal range, the outcomes were variable and only a minority of adults had achieved high levels of independence. Most remained very dependent on families or other sources of support.<sup>39</sup> In another study of individuals with IQ greater than 70, many had low levels of independence, poor social outcomes and lack of vocational achievement in adult life.<sup>40</sup> Many people with ASD, at all levels of IQ, are at a serious disadvantage in social relationships, employment, physical/mental health and quality of life. Next to nothing is known about aging adults with ASD.<sup>41</sup>

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<sup>33</sup> Shattuck et al., "Services for adults."

<sup>34</sup> J. Lounds Taylor et al., "Interventions for adolescents and youth adults with autism spectrum disorders," Agency for Healthcare Research and Quality Report 12-EHC063-EF (Rockville, MD: AHRQ Comparative Effectiveness Reviews, August 2012).

<sup>35</sup> P. Howlin and P. Moss, "Adults with autism spectrum disorders," *Canadian Journal of Psychiatry* 57, 5 (2012): 275-283.

<sup>36</sup> M. Selzer et al., "Trajectory of development in adolescents and adults with autism," *Mental Retardation and Developmental Disabilities Research Reviews* 10, 4 (2004): 234-247.

<sup>37</sup> Howlin and Moss, "Adults with autism."

<sup>38</sup> A. Levy and A. Perry, "Outcomes in adolescents and adults with autism: A review of the literature," *Research in Autism Spectrum Disorders* 5 (2011): 1271-1282.

<sup>39</sup> P. Howlin et al., "Adult outcomes for children with autism," *Journal of Child Psychology and Psychiatry* 45, 2 (2004): 212-229.

<sup>40</sup> M. Cederland et al., "Asperger syndrome and autism: A comparative longitudinal follow-up study more than 5 years after original diagnosis," *Journal of Autism and Developmental Disorders* 38 (2008): 72-85; I. Engstrom, L. Ekstrom, and B. Emilsson, "Psychosocial functioning in a group of Swedish adults with Asperger syndrome or high-functioning autism," *Autism* 7 (2003): 99-110.

<sup>41</sup> E. Fombonne, "Autism in adult life," *The Canadian Journal of Psychiatry* 57, 5 (2012): 273-274; Shattuck et al., "Services for adults."

## What are the Costs of Autism?

A systematic review by Amendah et al.<sup>42</sup> of 40 articles on the lifetime costs of autism established a lifetime range from \$1.2 million to \$4.7 million, depending on the severity of the diagnosis and levels of intellectual functioning. Cost estimates from the review fell into categories of: medical, non-medical (behavioural, residential, supported employment) and loss of employment income.

Ganz<sup>43</sup> estimated the lifetime per-capita incremental societal cost of autism at US\$3.2 million per individual; approximately US\$50,793 per year on average. Costs were broken down into direct medical costs (physician services, alternative medicine, health service utilization, equipment and home care), direct non-medical costs (child care, respite care, special education, supported employment) and indirect costs (lost productivity of both the individual and parent in the form of promotions not taken, switching to lower-paying jobs, more flexible jobs or leaving the workforce). The substantial cost amounts were primarily in the area of adult care and lost productivity of both the parent and individual with autism.

In the U.K., the lifetime economic cost of autism was found to be 1.23 million pounds (\$1.9 million Canadian) for someone with ASD and intellectual disability, and 800,000 pounds (\$1.2 million Canadian) for someone with ASD without intellectual disability.<sup>44</sup> Lifetime costs divided in these broad bands of ability were collected over a range of areas: accommodation, hospital services, respite, day services, family expenses, lost employment (both individual and parent), treatments and education.

To better understand the cost implications of parental burden of caring for a child with ASD, Jarbrink, Fombonne and Knapp<sup>45</sup> collected parental information about time spent on informal care via a pilot instrument of questionnaires and diaries. Parents thought that, on average, they spent nearly 60 hours a week caring and supporting their child due to the disorder and estimated that they lost 40 hours a week that they would have spent on other activities due to the child's disorder. Out-of-pocket expenses were also estimated and the total weekly costs were noted at 855 pounds (\$1,325 Canadian — the equivalent of \$68,900 per year). Costs were higher when the child had a learning disability than for a child without one. Findings indicated there was a wide variation of needs on the spectrum. The pilot of the instrument was found to be useful for children, but parents found it challenging to accurately note time and cost.

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<sup>42</sup> Amendah et al., "The Economic costs."

<sup>43</sup> M. L. Ganz, "The lifetime distribution of the incremental societal cost of autism," *Archives of Pediatric Adolescent Medicine* 161 (2007): 131-349.

<sup>44</sup> M. Knapp, R. Romeo and J. Beecham, "Economic cost of autism in the UK," *Autism* 13, 3 (2009): 317-336.

<sup>45</sup> K. Jarbrink, E. Fombonne and M. Knapp, "Measuring the parent, service and cost impacts of children with autistic spectrum disorder: A pilot study," *Journal of Autism and Developmental Disorders* 33, 4 (2003).

The cost impact of young adults with high-functioning ASD found that ASD resulted in high costs and indicated that a lack of supported employment for people with ASD may have added negative consequences for the economy. For 19 individuals, mostly with Asperger syndrome, the average annual cost for community support was 7,154 euros (\$9,443 Canadian). Costs were calculated for community supports (group homes, daily activities, personal supports), health-care usage, medications, employment supports (job placements, coaching) and project support (social groups, supportive conversations). Health-care costs accounted for 14 per cent of the total. Psychiatric services dominated the health costs for this population.<sup>46</sup>

Xiong et al.<sup>47</sup> found the total amount of annual financial burden was highest for families who had a child with autism, followed by families with a child with physical disability and mental disability. Autism was a significant predictor of family spending in the areas of education, medical, caring and clothing. In another study, the demands of ASD-caregiver time resulted in decreased family earnings by 21 per cent in comparison to families of children with other health limitations, and decreased by 28 per cent in comparison to families of children with no health limitations.<sup>48</sup> Clearly, ASD has a substantial economic impact on a family's financial situation.

In regards to general disabilities, a Canadian review of economic costs to families of children with disabilities by Burton and Phipps,<sup>49</sup> using PALS<sup>50</sup> data, found the majority of families with disabled children incur significant economic costs, explicitly in out-of-pocket expenses and the forgone employment opportunities of caregivers. Non-medical costs, such as added transportation to and from appointments or therapy, were also found. Labour-market problems, such as lost opportunities for parents, were associated with the severity of the child's condition.

The time costs of caring for children with severe disabilities living in the community compared to caring for children without disabilities was found to be significantly greater and does not decrease with advancing age.<sup>51</sup> Caregiving was a full-time job for 90 per cent of caregivers over their lifespan of adults with developmental disabilities.<sup>52</sup> Elevated time for care duties for an individual with ASD was found for mothers of individuals with ASD who reported significantly more time in child care, chores and less leisure time compared with a sample of mothers of children without disability.<sup>53</sup> It is clear that autism is an expensive diagnosis not only in terms of added financial burden on families, but also on the demands for the caregiver.

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<sup>46</sup> K. Jarbrink et al., "Cost-impact of young adults with high functioning autistic spectrum disorder," *Reach in Developmental Disabilities* 28 (2007): 94-104.

<sup>47</sup> N. Xiong et al., "Investigation of raising burden of children with autism, physical disability and mental disability in China," *Research in Developmental Disabilities* 32 (2011): 306-311.

<sup>48</sup> Z. Cidav, S. Marcus and D. S. Mandell, "Implications of childhood autism for parental employment and earnings," *Pediatrics* 129, 4 (2012).

<sup>49</sup> P. Burton and S. Phipps, "Economic costs of caring for children with disabilities in Canada," *Canadian Public Policy* 35 (2009): 269-290.

<sup>50</sup> PALS — the Participation and Activity Limitation Survey — is a large, nationwide, Canadian data set used in the research for a representative sample of Canadian children with disability.

<sup>51</sup> A. L. Curran et al., "Time costs of caring for children with severe disabilities compared with caring for children without disabilities," *Developmental Medicine and Child Neurology* 43, 8 (2007): 529-533.

<sup>52</sup> K. Dillenburger and L. McKerr, "40 years is an awful long time: Parents caring for adult sons and daughters with disabilities," *Behavior and Social Issues* 18 (2009): 1-20.

<sup>53</sup> L.E. Smith et al., "Daily experiences among mothers of adolescents and adults with ASD," *Journal of Developmental Disorders* 40 (2012): 167-178.

## The ASD-Caregiver Workforce

Little was found in the literature regarding the workforce of ASD-knowledgeable workers. Gerhardt and Lainer<sup>54</sup> note that the U.S. Department of Health and Human Services found the average staff turnover rate for those serving adults with developmental disabilities was 50 per cent. This rate of turnover would be considered debilitating in other industries. The reasons most often cited for high turnover were insufficient staff-to-client ratios, low pay/inadequate benefits, physical and behavioural challenges presented by clients, inadequate training, and limited professional status. The lack of qualified and available staff is an issue for adults with developmental disabilities.<sup>55</sup> In a 2012 review of the demand for autism workers in California, it was found that the increased prevalence of autism increased the wages and increased the demand for ASD providers over non-autism health-worker positions. This study indicates that the market for ASD-knowledgeable workers responds when increased demand for care and support exists.<sup>56</sup>

## NEEDS MAP

The heterogeneity of autism is vast, and few studies have analyzed the implications of these challenges on the delivery of services and the significant impact on service needs.<sup>57</sup> Although it is clear from research regarding support-needs that many individuals living with ASD need a range of lifetime supports, who needs what, what type of supports provide best outcomes, and what the costs are remain unclear. A better understanding of the spectrum of supports needed and the costs of that support in a Canadian context may help Canadian society to better address the heterogeneity of needs.

To address this gap in research, we created a “needs map” to better understand the supports needed across the spectrum and over the lifespan. The needs map (Appendix A) outlines the support-care needs and costs for three hypothetical individuals living with ASD at different life stages. The needs map is an artificial construct and is solely intended to illustrate the variation of needs and estimate the costs for meeting the needs of three individuals at different points on the spectrum. Three unique individuals living with ASD are represented as case studies in the needs map and were chosen in an attempt to represent the diversity of the spectrum and not all individuals on the spectrum: 1) Person A: male, severe autism, non-verbal, IQ below 70 (age equivalent of three to six years old); 2) Person B: male, IQ over 70, language delay 3) Person C: female, Asperger syndrome.<sup>58</sup> Supportive-care tasks were considered to be the type of support required, at a minimum, to maintain basic skill levels, and assure safety and basic quality of life (access to health care and community integration).

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<sup>54</sup> P. F. Gerhardt and I. Lainer, “Addressing the needs of adolescents and adults with autism: A crisis on the horizon,” *Journal of Contemporary Psychotherapy* 41 (2011): 37-45.

<sup>55</sup> L. P. Lin and J. D. Lin, “Job burnout amongst the institutional caregivers working with intellectual and developmental disabilities: Utilization of version of the Copenhagen Burnout Inventory survey,” *Research in Autism Spectrum Disorders* 7, 6 (2013): 777-784.

<sup>56</sup> D. Dave and J. Fernandez, “The effect of an increase in autism prevalence on the demand for auxiliary healthcare workers: evidence from California,” National Bureau of Economic Research Working Paper 18238 (2012).

<sup>57</sup> Shattuck et al., “Services for adults.”

<sup>58</sup> Case studies adapted from P. Szatmari, *Understanding ASD Sub-types, in Forgotten: Ontario Adults with Autism and Adults with Aspergers* (Autism Ontario: 2008) and from personal communication, November 2011.

In the absence of clearly outlined interventions for adults that address the heterogeneity across the spectrum over the lifespan, this estimate of needed supports and costs was considered the best approach to address gaps in support. This approach is similar to research noted in the literature review where journals were used to estimate time logged for support, but differs from that research by taking an approach that describes the heterogeneity of autism.<sup>59</sup>

To summarize, the needs map was used in this project to:

- Identify the vast range and levels of care and support tasks and time needed for individuals living with ASD beyond the care and support needed for a neurotypical individual comparator in the same life stage.
- Estimate the value of caregiver time required to provide that supportive care.
- Provide a framework to search for provincial policies that exist to meet the needs and to then compare the policy findings and consider how well Canadian society is doing to address the needs.

### **Estimating Needs and Costs**

To understand the type of supportive-care needs, a range of tools and scales were reviewed to help categorize areas of supportive care. Professionals and policy-makers are familiar with the numerous scales and tools available that are often used to assess functional ability, create individual program plans and/or to allocate funding. Some examples of tools available to professionals include the Supports Intensity Scale (SIS), Scales of Independent Behaviour – Revised (SIB-R), Assessment of Basic Language and Learning Skills (ABLS), Assessment of Functional Living Skills (AFLS) and the Alberta Foster Care Placement Needs Scoring.

Elements of these scales were used in the needs map to clarify the type of support required by another to assist individuals with ASD. We choose categories most often needed for the basics of daily living, but other real world categories of support used by families could be added to this list; hence, this list is may not represent all the possible supportive care tasks employed in real life. For example, the use of alternative therapies and special diets can be very time consuming.

Categories of supportive care are summarized as:

- Self Care (bathing, toileting, eating, and personal hygiene)
- Home Living (cooking, laundry, home maintenance)
- Service Co-ordination (overseeing treatment programs, hiring staff, paperwork)
- Personal Organizing or Executive Functioning (banking, co-ordinating recreation/social)
- Health and Safety Management (overseeing medical, dental needs, supervision or vigilance)
- Adult Day Opportunities or Employment (job coaching, finding jobs, teaching skills, enabling community integration, volunteering)

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<sup>59</sup> The needs map was created based on literature reviews and peer reviews with local ASD agencies, clinicians and researchers. ASD as a spectrum condition will most likely be represented by a continuum of needs and costs. In reality, the needs and costs will range from extremely high to zero, depending on the individual level of independence.

- Transportation (driving, supervising on public transit, teaching transit skills)
- Advocacy (complaining, writing, working with agencies, meeting)
- Social Skills/Communication/Behaviour and Sensory Management

It is likely that any supports will be most successful when they address the individual's uniqueness in terms of communication, social, sensory, behavioural needs and physical and/or mental health conditions.

### **Assumptions in Needs-Map Cost Estimates**

Costs were calculated in the age bracket covering the years 14 to 17 (adolescence) and 18 to 64 (adulthood). Costs were calculated during this specific period of time for several reasons. Our interests are to bring attention to the lifespan period where the least amount of supports and knowledge exist, and where it is very clear a delineation of caregiver time and cost between neurotypical and individual with ASD is present. We acknowledge that caregiver costs will exist for all children in early childhood. Costs are likely higher for children living with disability, but starting in the adolescent years it becomes quite apparent that many individuals with ASD continue to need support in comparison to their neurotypical peers. The lifespan time and cost methods used in this report are not clouded by the debate of how much caregiver time is required to raise a normal child, thus the care costs estimated could underestimate the full lifespan care and support costs for an individual with a neurodevelopmental disability.

In the aging years, starting at age 65, neurotypicals begin again to need support due to aging. These neurotypical needs start to cloud the clear calculations of the care-support costs between the neurotypical and individual with ASD. Again, it is possible that neurodevelopmentally disabled elderly will need more time and care than the typical aging adult, but the exact calculations of this time are not yet clear. As well, government services and supports are more readily available for all aging individuals at age 65. These supports are provided in the form of dementia daycare programs, long-term care or home-care supports; although not ASD specific, they are services provided to meet care-time needs that would be accessible to individuals with ASD. Finally, we acknowledge that there will be some caregiver support for a normal 14-year-old (co-ordination of higher level activities), but costs will be minimal, progressing to none by age 18.

The approach to estimate costs uses a replacement-cost method to estimate value of caregiver time.<sup>60</sup> We assume that the intensity and amount of needs will remain constant for each of the individuals over the life stages. We make this assumption because the literature-review findings indicate that not enough is known to chart the trajectory across the spectrum and adult outcomes are uncertain. The three individuals in the needs map do not progress nor do they regress, but continue to need the same amount of support over the life stages.

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<sup>60</sup> Our work builds from a report commissioned by Dr. Emery from Brown Economic Consulting Inc., based on information from an occupational-therapy report on the time to replace the caregiver time that had been provided by the deceased parents of a hypothetical 10-year-old boy with severe autism in Alberta. Brown Economic Consulting used two methods to value that caregiver replacement. One approach values the total care-giving time requirements at market wages, while another "global replacement method" uses the cost of foster care.

For the purposes of this project, and to simplify the calculations of time in the needs map, we have assumed that each of the three individuals have no severe behaviours<sup>61</sup> and no coexisting mental or physical health issues. The three case studies could be considered uncomplicated situations although, in reality, each individual most likely lives with some additional challenges. If these complicating factors are present, regardless of IQ, and if the individual lacks the complete independence to oversee health issues (is unable to co-ordinate appointments, travel to appointments, schedule medications, troubleshoot emergency situations and/or manage sensory or behavioural problems) then it is most likely that added support time will be required and, consequently, caregiver costs will rise. A list of other assumptions can be found in Appendix A.

The costs outlined here are above and beyond the added costs noted in previous research of increased use of professional time in areas of medical health (doctors, nurses, and emergency department staff), mental health, criminal justice, psychologists and speech therapists.

## **LIFE STAGES AND COSTS**

### **Life Stage 1: (ages 14–17)**

Adolescence is a period of time when neurotypical individuals begin to move towards complete independence and where the school system provides a considerable amount of daytime support. Around this age, most neurotypicals begin to drive a car, can take a bus, hold a summer job, look for new employment, complete school requirements and enter post-secondary institutions, partake in independent recreational and social activities, and be left at home alone for some periods of time.

All individuals moving towards adulthood must navigate numerous transitions. Some of these transitions include: puberty, the end of publicly funded school, consideration of career and employment opportunities, further education at post-secondary institutions, relationship development and possibly moving away from the family home. Although difficult, most quickly gain the skills required for independent living. The gap between lessening supports needed by the neurotypical 14-year-old and the continuing supports needed for the individuals with ASD becomes obvious. The continued need for lifelong supports is a disruption of the neurotypical family life cycle and it is clearly apparent at this stage.

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<sup>61</sup> An example of mild, lifelong behaviour problems might include behaviours of repeated complaining, chronic fixation on topics, poor judgment, becoming tearful easily, incessant talking and repeated questions. Although stressful and frustrating, these milder behaviours likely require less intense support and time. Challenging behaviours can be defined as behaviours that include self-injurious behaviour, physical and/or verbal aggressions, destructiveness, inappropriate sexual behaviour, antisocial behaviour, disturbed sleep and over activity (James, “The formal support”). It is likely challenging behaviour require a higher level of time and perhaps skill, maybe even strength — in some cases, requiring two people to manage — but these assumptions are not confirmed in research.

**PERSON A: COST \$131,893 PER YEAR**

Person A, a more severely affected individual, requires supportive care 24 hours a day, seven days a week. Supportive care is needed in every area of daily life and ranges from hands on, “doing for” care tasks to teaching independence in daily living. Higher-level executive-functioning tasks and co-ordination tasks or advocacy will be the complete responsibility of the caregiver. Safety concerns are high due the lack of understanding of basic safety issues and this necessitates regular vigilance throughout the day and night.

The cost for this type of supportive care could range from \$94,775 (based on costs from the Brown Economic Consulting report for replacement value of caregiver time for a 10-year-old severely autistic boy), up to \$131,893 per year in the needs map in this report. Increases in costs in the needs map are due to the fact that there are no free regular evening programs for Person A, no free available weekend programs, and an adolescent has a later bedtime hour than a 10-year-old. The presence or absence of free and appropriate programming will significantly impact the amount of caregiver time needed. Time calculations will vary on an individual basis.

**PERSON B COST: \$74,626 PER YEAR**

Person B, a moderately impacted individual, is verbal but often has difficulty finding the correct words for the right situation, leaving him unable to express himself appropriately. He lacks planning ability to the degree that he may forget the sequence of morning preparation (washing, dressing, brushing teeth) without a schedule. He is unable to drive or take complicated public transit routes independently, but can walk to regular destinations such as school. He lacks understanding of social cues and typical social interactions. He is able to be left alone for short periods of time, but requires some intermittent day supports and needs someone available at night in case something unexpected was to happen and he could not cope.

**PERSON C COST: \$26,639 PER YEAR**

Person C does well academically but lacks understanding of social norms and lives with sensory challenges that she has learned to cope with (avoids public transit during busy times due to noise sensitivity, wears headphones when needed). With extra intermittent and life-coaching type of supports and strategies she is able to establish relationships, learn to drive a car and complete her educational requirements. She has exceptional talents in creative arts and technology and is focusing on website design in school. She struggles adapting to new situations and hence social skills learned in one setting do not always transfer to other settings.

Person C has no need for hands-on daily living care. She is capable of independent bathing, dressing and meal preparation but needs help with social-skills supports, employment coaching, executive-functioning tasks (banking, planning) and crisis supports for unexpected situations. She can remain at home alone for longer periods of time than the other two individuals, but needs someone to check on her intermittently for planning-type tasks (more complex meal preparations, social-skills questions, planning and co-ordinating work). Although Person C has a fairly high level of independence in comparison to the other two, regardless of her IQ she still does not comprehend important life skills and is not fully independent. She needs ongoing support to maintain her current ability and to continue to learn.



## **Life Stage 2: (ages 18–64)**

For many neurotypicals this is a complex and active stage of life. Neurotypicals may complete post-secondary education, enter the workforce, try different careers, find a lifelong partner, raise a family and become homeowners. They may seek out recreational and leisure experiences. All of these life transitions and experiences are managed by most neurotypicals independent of external supports.

Given the statistics for many living with ASD (most live at home, are not married, are underemployed and isolated, with high rates of mental health issues) we can assume that many have support needs during Life Stage 2. At a minimum, supports must help individuals retain current skill levels and ultimately supports will help them to continue to learn and grow, always moving toward optimum attainable independence.

The loss of the day supports from the publicly funded educational system leaves a significant gap in daytime structured activity resulting in unmet needs. For most neurotypicals, this time is filled with employment or ongoing education. For individuals with ASD, where the primary and secondary school system provided daytime support, the advanced education does little to address ongoing life-skills education needed by many. Increases in costs across the spectrum at this life stage are a reflection of the loss of school supports.

### **PERSON A: COST \$158,359 PER YEAR**

Person A continues to be non-verbal with a limited understanding of community and home safety. He is unaware of danger in his home and is unaware of community dangers such as predators, street safety and other basic safety issues. For these reasons he still needs 24-hour supervision. He demonstrates mild behavioural issues (non-compliance and perseveration on items) and still needs support for daily living (meal preparation, bathing, grocery shopping, and transportation). He needs full support for all higher-level tasks of planning, advocacy and health management.

### **PERSON B: COST \$82,769 PER YEAR**

Person B continues to struggle in understanding social norms and using his words to communicate. He still needs supports for self-care tasks in the form of schedules and some reminders to fully and independently complete some of these tasks (appropriate clothing, hygiene, meal preparation, post-secondary school support). This individual has excellent skills for the right job. He is focused and detailed but lacks the ability to find the right job, get to the job, interview, and retain the job without help. He is capable of staying at home alone during the day and so, in the absence of structured employment opportunities or day programs and supports, he may become what one community agency in Alberta refers to as the “basement dweller.” These are individuals with ASD, capable of being left alone for short periods of time and who may have skills for community integration or employment, but lack supports needed for employment, and thus remain in the family home with limited supervision and unstructured days.

### **PERSON C: COST \$30,711 PER YEAR**

Costs for supportive care are not needed every day for Person C (as they are for the other two individuals); instead, time is needed for occasional support (life-skills and employment coaching) plus occasional emergency assistance. Person C is living with her partner, she is able to drive a car during certain periods of the day, she holds a job and is coping very well overall. However, she still lacks the understanding of social norms and the higher-level executive-functioning skills needed to manage finances. As a result, she continues to need support to manage finances and higher-level co-ordination tasks. She may at times need intermittent emergency assistance when difficult and unexpected challenges arise. Emergency assistance would be in the form of more intensive short-term supports that would help her to manage difficult transitions or unexpected emergencies, like job loss, car break-downs, marital problems or housing changes.

### **Summary of Lifetime Costs above a Neurotypical (ages 14–64)**

As a straight sum over the ages of 14 to 64, the lifespan value of caregiver time needed for Person A is approximately \$5.5 million. That would be the equivalent of telling a family at the age of diagnosis of a Person A (typically, at age two), that they need to make a lump-sum investment on that day of \$1.6 million (invested at five-per-cent interest) to pay for the lifetime costs of care and support that their loved one will need. These costs are in addition to previously calculated costs of added medical professionals such as language pathologists, occupational therapists, and psychologists, and added out-of pocket expenses, such as special equipment or diets.

In essence, any individual who needs 24-hour support seven days a week will cost at least \$158,359 per year of after-tax income. That would mean that a family needs an annual income of well over \$200,000 to pay for the care and support of a high-needs individual. If Persons B and C were to develop severe behaviours or added mental and physical health problems and were unable to independently oversee all behavioural management plans, co-ordinate medical appointments, oversee treatments, manage frustrations or aggression, and thus required 24-hour supervision, support costs would then increase. At the ages when neurotypicals are independent and require little to no added caregiver support time, the individuals living with ASD who may lack the full skills of independence will require added support, and support costs may increase in more complex situations.

### **HOW IS ALL THAT CARE PAID FOR?**

The annual values of caregiver time described above are enormous and they are well beyond what the individuals with ASD and their families could pay for out of annual income. Provision of this supportive care over a lifetime requires the time and resources of others and must be paid for in some way. For someone like Person A, they would need the equivalent of an annual income of over \$158,000 per year just to meet basic supportive-care needs. Only around 10 per cent of Canadians, typically those with no disabilities and working full time can be expected to have an income that high, which in most cases must be used to pay for the typical full needs of a family. With the high costs of care required, these families would be left

with nothing to live on.<sup>62</sup> In an analysis of Canadian data comparing families with no disability, families with physical disability, and families with “other limitations,” such as the neurodevelopmental disability of autism, Clarke et al.<sup>63</sup> found the median household incomes for Canadian families with no disability was in the range of \$60,000 to \$79,000; for those families with physical disability the range was \$50,000 to \$59,000; and for those with “other limitations,” the annual income was less than \$50,000. Comparing the annual incomes to the yearly care time required, it is clear that the majority of Canadians with ASD dependents must somehow juggle a variety of ways to pay for lifelong care.

Currently, Canadian society uses a variety of ways to pay for care and support time for individuals with ASD who need support. Below is a list of the ways to pay for the support time needed.

- 1) **Government Pays:** Where government supports exist for families to pay for outside caregivers or to compensate caregivers in the home, this equates to a transfer of financial burden from the family to the broader taxpayer.
- 2) **Family Pays:** Households of the individual with ASD can choose to use their own funds to employ caregivers.
- 3) **Family Does:** Households can provide care services themselves, which is reflective of a household production model. In situations where the high financial costs of care exceed available government funds, many families are left in the position that their own time is the only affordable way of providing care. The value of this time is often interpreted to be their foregone market earnings, but to that value must be added the depreciation cost associated with declining physical and mental health of the caregiver.
- 4) **No Care:** The individual with ASD pays in terms of unmet needs and increased risks of accident and injury in the case of the “No Care” scenario, where an individual who should have some level of support to survive or even thrive is left alone for periods of time (from a few minutes to a few hours, usually as a last resort) in the hope that they will manage.
- 5) **Unqualified Providers or Inadequate Care:** The individual with ASD pays in terms of unmet needs and increased risks of accident and injury through the hiring of cheap labour or inadequate labour. In this scenario, a support person may be inexperienced or unsuitable for handling the unique needs of the individual, but works for less money, or is the best option where no caregivers are available (e.g., an untrained, inexperienced worker hired to assist a large-sized adult with ASD who has occasional severe behaviours, or a situation where two caregivers should be present to manage behaviours but only one can be afforded).
- 6) **Volunteers:** Volunteers provide support with no financial compensation. Friends or extended family and even strangers may be willing to provide their own time with no compensation. Volunteers offer supports in a variety of recreational and social settings. There are other volunteer models used in the disability community in which extended family and friends form networks of support surrounding the individual with disability to ensure quality of life when parents are no longer able to do so. Although these are not costs to the individual, they are still costs in terms of time for the volunteers.

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<sup>62</sup> For families with vast financial resources these huge costs may be inconsequential, but regardless of the availability of finances, there remain the problems of finding and retaining qualified ASD workers.

<sup>63</sup> M. Clarke et al., “A basic annual income for the neuro-developmentally disabled in Canada,” *Options Politiques* (May 2012).

- 7) **Private Funding/Philanthropy:** Other sources of funding in Canada might include fundraising contributions from private donations, but these funds do not provide a reliable or predictable source of assistance and are not typically sought on an individual basis. Dollars from private sources do offer, in some cases, substantial relief and support for individuals and families, often in the form of community-run group programs, support groups, after-school programs and special ASD camps. These, again, are costs not paid for by the individual but paid for by members of society.

To summarize, the current Canadian modes of caregiver support combine a range of these ways to pay. There was no research found that indicated the proportion of who pays how much. We assume that where community infrastructure systems falter, and if government funds are limited, then the majority of supportive care will fall to the family. These families make less income than non-disabled families and are faced with added out-of-pocket expenses.<sup>64</sup> This underscores the importance of not only considering basic income of ASD families, but also the importance of the associated costs of care for an individual with a neurodevelopmental disability, making the purchasing power of these households much less than that of non-disabled families.<sup>65</sup>

## PROVINCIAL POLICY REVIEW

### Provincial-Policy Data Collection

The next step in the project was to understand what exists in Canadian policy to address support needs of the three unique individuals living with ASD across the lifespan. A scan of the provincial policies and programs that exist to meet the needs of Persons A, B and C across provinces was completed by searching provincial government websites for policy and program-dollar amounts to support individuals with autism in adolescence and adulthood. Other care-related policies or programs relevant to ASD supportive care, when found, were also recorded (respite programs and caregivers supports).

Government websites were searched from September 2012 to February 2013. Six Canadian provinces were the focus of the search including: British Columbia, Alberta, Saskatchewan, Manitoba, Ontario and Nova Scotia. Limitations of Internet search methods are noted.<sup>66</sup> Please see Appendix B for summary findings. For the detailed findings and policy inventory please contact the authors.

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<sup>64</sup> Ganz, "The lifetime distribution."

<sup>65</sup> Clarke et al., "A basic annual."

<sup>66</sup> Website designs and location of information change; provincial government websites are set up differently, whereby a search term on one site leads to related government services, while in other provinces it might lead to programs outside of government; websites often give only partial information; claims from sites in terms of quality cannot be confirmed; and conclusions from Internet searches may represent trends only.

Overall, it was difficult to find the exact dollar amounts allocated to ASD youth and adults in each province on government websites. Where amounts were found, they were placed into the appendix. Reasons for not finding specifics were as follows: not all governments posted annual budget reports; allocation of dollars in budgets are usually noted for all individuals with disability and not separated by condition and governments did not often advertise on websites the average amounts available to eligible individuals or maximum amounts;<sup>67</sup> entitlements are not stipulated, so supports are “discretionary.”

For the reasons above, several pan-Canadian reports were used to fill in data not found on the government sites. These documents included 1) Parliamentary Information and Research Service: Provincial and Territorial Funding Programs for Autism Therapy;<sup>68</sup> 2) British Columbia Deputy Minister’s Review of Community Living British Columbia: Improving Services to People with Developmental Disabilities;<sup>69</sup> 3) Nova Scotia Department of Community Services: Community Supports for Adults Renewal Project: Jurisdictional Review Summary Report.<sup>70</sup>

The findings do not reflect the availability or quality of services or the struggles that families or individuals may undertake in regards to wait lists, lack of residential placements, lack of appropriate programs, and lack of trained staff. Nor do the findings reflect where families may find these supports adequate and even generous for meeting their needs.

### **Canadian Trends in ASD Policy**

The six provinces reviewed differ greatly in policy initiatives and funding for ASD, but some trends can be extracted from this review based on the state of services at the time of this research. Starting in the early years (pre-school age), all provinces reviewed were found to offer specific behavioural-based intervention programs, frameworks and funding for young children, while many specifically mention autism and IBI (Intensive Behavioural Intervention) or ABA (Applied Behavioural Analysis) approaches.

As children with ASD age into the education system (around five years of age) the supports become more broadly administered as supports for children with disabilities, providing a range of supports such as respite and behavioural supports. However, provincial amounts vary considerably. The supports for children with disabilities continue up until age 18 or 19. As well, funding for school supports as part of the education system begins at school age, although these policies were not specifically examined in this report.

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<sup>67</sup> Nova Scotia Department of Community Services, Community Supports for Adults Renewal Project: Jurisdictional Review Summary Report (2004), 44 notes that one province did explain that maximum amounts available could be as high as \$238,000 per person per year.

<sup>68</sup> Parliamentary Information and Research Service, Library of Parliament, Provincial and territorial funding programs for autism therapy (2006). No further data had been collected since 2006.

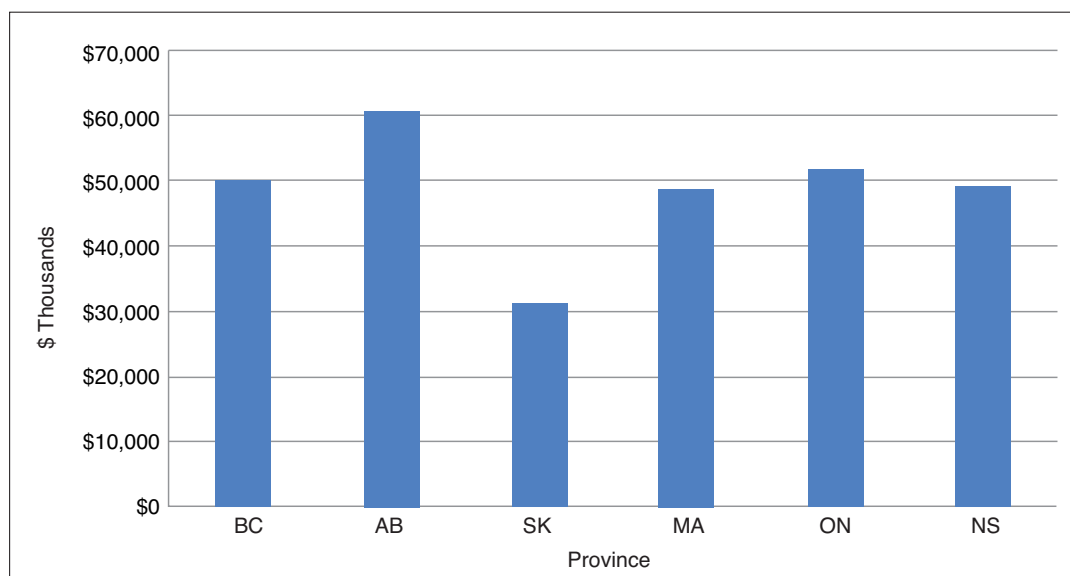
<sup>69</sup> Deputy Minister’s Review of Community Living British Columbia: Improving Services to People with Developmental Disabilities (2011).

<sup>70</sup> Nova Scotia Department of Community Services, Community Supports for Adults Renewal Project.

Into adulthood, provincial government models of service delivery and management for the needs of persons with disability differ between provinces. Most provinces have separate departments of community services and health. Community-services ministries usually deliver supports for adults with developmental and intellectual disabilities.<sup>71</sup>

Provinces vary on the average amounts provided for adults with developmental disability. From the chart below, from British Columbia’s Deputy Minister’s Review of Community Living, the provincial funding for adults with developmental disabilities varied and often used IQ level as a criterion. The B.C. deputy minister agreed with the findings of the internal auditor in this report regarding the dollar amounts presented in the chart, but this report did not detail the provincial sources of dollar amounts. The Alberta amount in this document is approximately \$60,000, but in a KPMG report, the average adult amount funded by the Persons with Developmental Disabilities (PDD) program is \$48,387 (total number of individuals supported in 2010 divided by total budget less administrative costs).<sup>72</sup> As there is no explanation in the B.C. report on the source of the dollar amounts, it is difficult to know the true average amount one would receive in Alberta if eligible.

**AVERAGE FUNDING PER INDIVIDUAL 2010-11**



The IQ criterion for funding that was not found for youth existed for adults across all of the six provinces reviewed and so those eligible for child and youth supports based on severity may not be eligible as adults because of their IQ. Individuals with ASD who have higher IQ (usually higher than 70 or 75) but who still struggle with adaptive-functioning skills may not receive any funding supports. This was found to be the situation at the time this report was written. Persons B and C would fall into this category. Saskatchewan differs at this point by continuing to designate specific funds for those with ASD up until the age of 24, not based on IQ.

<sup>71</sup> This finding was also confirmed in: Nova Scotia Department of Community Services, Community Supports for Adults Renewal Project, 3.

<sup>72</sup> KPMG, Summary Report to the Minister, Ministry of Seniors and Community Supports, *Administrative Review of the Persons with Developmental Disabilities (PDD) Program* (October 2010), <http://humanservices.alberta.ca/documents/pdd-ar-summary-report.pdf>.

All six provinces have home-care programs.<sup>73</sup> Similarities across provinces exist in what is offered: a range of basic services, care management, nursing services, home supports including home-making, Meals-On-Wheels and respite services. Eligibility was also similar across provinces in that care is in response to unmet needs and lack of sufficient support (lack of sufficient help from family and friends). Under this definition, some adults living with ASD with a higher level of independence, no funding and lacking family support could receive home-living assistance. However, in many jurisdictions more than 90 per cent of home-care recipients were over the age of 65 and their caregivers were likely to be elderly spouses. This suggests that individuals with ASD may not be accessing home-care supports.<sup>74</sup>

Mental health services and disability employment programs were not the focus of this review, but where they exist it is possible that these would assist individuals with ASD who have mental health challenges or those who are unemployed, regardless of IQ.

Income supports vary across provinces and in a detailed review of three provinces, Alberta's Assured Income for the Severely Handicapped (AISH), for adults with disability in need of a basic level of income, was found to be the most generous.<sup>75</sup> These funds are primarily used for food, clothing and housing costs but not for caregiver time. The amount per individual could be as high as \$1,588 per month, depending on eligibility.

In addition to these trends across provinces, several unique provincial government initiatives for ASD, found in the policy scan, are noted below.

- In British Columbia, the Cross Ministry Transition Planning Protocol for Youth with Special Needs is a multi-ministry transition protocol for special-needs children to facilitate transition to adulthood. The protocol was jointly developed and endorsed by six ministries and relevant government agencies to improve access to existing resources and supports and to ensure a co-ordinated transition process. No dollar amount was found specific to this initiative.
- In Saskatchewan, the Cognitive Disability Strategy is directed to individuals with FASD and ASD. This strategy is intended to provide services to address the unmet needs of people with cognitive disabilities up to the age of 24. Eligibility is not specifically tied to IQ score; funds are available with an autism diagnosis and can be used to help individuals with activities of daily living, such as keeping appointments, taking medications and grocery shopping. The Cognitive Disability Flexible Funding Benefit is issued to the family member or service following an assessment and development of a support plan. No dollar amount was posted in the website.

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<sup>73</sup> The general purpose of home care in Canada is to provide: 1) a substitution for services provided by hospitals and long-term care facilities; 2) a maintenance function to allow clients to remain independent and prevent the need for a new, more costly facility; 3) a preventative function that invests in service and monitoring to lower longer-term health costs. (Provincial and Territorial Home Care Programs: A Synthesis for Canada, June 1999, <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/1999-pt-synthes/index-eng.php#s1a3>).

<sup>74</sup> Janet Dunbrack, *Respite for Family Caregivers: An Environmental Scan of Publically Funded Programs in Canada* (Health Canada: 2003), 4.

<sup>75</sup> Income Supports for Persons with Disabilities, University of Calgary School of Public Policy (2011), [http://policyschool.ucalgary.ca/sites/default/files/research/disabilitiessept\\_0.pdf](http://policyschool.ucalgary.ca/sites/default/files/research/disabilitiessept_0.pdf).

- The government of Manitoba has developed “Thrive” (a provincial autism plan) that outlines 10 initiatives for autism. Of specific interest to adolescents and adults are the initiatives in the Thrive document entitled: “Becoming More Independent,” which supports life-skill programs and transitions to adulthood; “Adult Services,” intended to help adults meet their full potential in the workplace; “Building ASD Awareness,” which supports training of professionals and the public; and “Staff Development and Recruitment,” which promotes collaboration with universities to develop autism-specific training programs and to enhance recruitment strategies to attract students to this specialized field. Manitoba was the only province to have an ASD provincial plan that considers ASD-lifespan needs.
- Nova Scotia offers an Independent Living Supports (ILS) Program that provides up to 21 hours a week of supports and services based on functional assessment and unmet needs that is not IQ-based. To be eligible, the individual must be under the age of 65 and have a high level of independence. Funds can assist individuals in maximizing independence in daily activities (maintain a household, laundry, shopping and banking, preparing meals, transportation for community access) as well as participating in leisure, volunteer or work activities, and promotion of health and wellness.

### Value of the Gaps

For the three individual case studies there exists a value gap across the lifespan for each individual. Where government funds do not cover full costs, supports must be paid for in other ways previously described. In situations where community infrastructure is lacking (quality housing, in-home and out-of-home respite, quality and available day programs or employment supports), the majority of cost falls on families and the quality of life for both individuals and families may suffer.

A more severe individual requiring 24-hour support regardless of IQ could cost, in terms of value for replacement of caregiver time, approximately \$131,000 per year as an adolescent and \$158,000 per year as an adult. In Alberta, assume Person A could receive up to \$40,000 per year and, as an adolescent and as an adult with an IQ of 70 or below, will average \$60,000 in support costs with no maximum stated. The value of the gap in adolescence is \$91,000 and in adulthood is \$98,000. If Person A needs \$158,000 per year immediately at age 18 due to a family inability to support, would that maximum amount be available in any province? As governments did not often give maximum amounts, it is possible that it would be available, but in some cases perhaps not.<sup>76</sup>

Similarly, if we take a Person B who needs about \$74,000 as an adolescent and \$82,000 as an adult, with no severe behaviours, or co-morbid conditions, and assume as well that he could access up to \$40,000 in Alberta if needed but when he turns 18 he gets no support because of his higher IQ, then the adolescent gap is \$34,000 and the adult gap is \$82,000. Similarly for Person C there will be a gap in support costs as an adult due to IQ eligibility. However if one adds in for Person B or C the severe behaviours, unmanaged sensory issues and physical or mental health conditions the costs may begin to rise. These costs could rise as high as \$158,000 for any person in need of 24-hour support, seven days a week. If adult Person B or C is ineligible due to IQ and there are no other clear avenues of funding available, then they could be faced with a very high gap in support costs.

<sup>76</sup> Monsebraaten, “Frantic Parents Search.”



## Gaps in Community Services and Family Stress

Numerous provincial community-consultation reports indicate that gaps exist in community services for individuals with autism, especially for adults. In Nova Scotia, a province-wide survey of the lifespan needs for persons with autism by the Autism Management Advisory Team<sup>77</sup> found gaps in services for adults. Basic and practical needs were not being met. Approximately one-third of survey participants needed employment and day-program activities, social programs, post-secondary programs, housing options and activity-based programs.

Autism Ontario<sup>78</sup> notes the current framework for care does not match the complex and ongoing needs of adults with ASD. Recommendations in this report specifically noted the need for day supports including vocational and employment options, educational, social and recreational services, supported living options and professional supports. Ontario families were frustrated with uncoordinated, severely lacking or limited services and supports for adults.<sup>79</sup> Services for youth and adults are widely needed in areas of recreational programs, advocacy/case-management, medical emergency services, psychiatric crisis service, recreational day programs and employment services.<sup>80</sup>

In Alberta, a province-wide community caregiver consultation from the Alberta Disabilities Forum<sup>81</sup> identified three key challenges across the province including: finding and retaining well-qualified and professional caregivers, finding suitable respite services, and coping financially. Specific to autism, focus groups of young adults and families transitioning into adult services noted the following areas of concern: difficulty accessing adequate and appropriate information, limited and inappropriate adult service providers, wait lists for services, ineffective service, lack of qualified and professional staff, reduced opportunity for community access or recreational activities, lack of post-secondary program opportunities, few employment opportunities and a general lack of support for transitioning into adult services.<sup>82</sup> In Alberta, staff turnover, retention and training is an ongoing problem. “Where good quality staff exists families feel their family member grows, learns, participates more in community and becomes more independent. Family members find they are much less stressed.”<sup>83</sup> Autism Calgary, in a review of adult-service needs, found that parents often commented on the lack of affordable and competent staff to support families and to work with individuals.<sup>84</sup>

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<sup>77</sup> Autism Management Advisory Team (AMAT), Report on Lifespan Needs for Persons with Autism, Nova Scotia Department of Education (2009).

<sup>78</sup> Autism Ontario, *Forgotten*.

<sup>79</sup> Stoddart et al., “Diversity in Ontario’s.”

<sup>80</sup> K. P. Stoddart, L. Burke and R. King, *Asperger Syndrome in Adulthood: A Comprehensive Guide for Clinicians* (New York: Norton, 2012).

<sup>81</sup> Alberta Disabilities Forum, *Caregiver community consultation: A report on the findings* (November 20, 2008).

<sup>82</sup> Autism Society of Edmonton Area, *Young lives, bright futures?* (2007).

<sup>83</sup> *ibid.*

<sup>84</sup> Autism Calgary Association, *Adult life with autism spectrum disorder: A self-help guide* (2009).

There is no lack of research on the stress families face as they attempt to support their individual with ASD. Lifelong care giving is extremely stressful not only financially, as outlined in the literature review of this report, but also from a mental and physical health perspective. Families of children with autism suffer adverse emotional and social consequences of caring for the child with ASD.<sup>85</sup> Myers, Mackintosh and Goin-Kochel<sup>86</sup> found that mothers of children with autism experienced higher degrees of stress than mothers of other children with developmental disabilities. Studies in caregiver literature have documented the adverse impact on caregiver health outcomes due to the impact of caregiver strain.<sup>87</sup> Less is known about the experiences of older parents of autistic adults. Hines, Balandin and Togher<sup>88</sup> found that older parents did not believe formal services adequately supported their ability to care in a family context. Older people caring for adult sons and daughters with developmental disabilities are under tremendous stress. Not only do they suffer their own health problems, they also may experience financial loss from lifelong caregiving and often exist in the virtual absence of structured futures planning.<sup>89</sup>

More research on aging caregivers of adults with ASD is needed. Relying on family to shoulder the lifelong burden of care in the face of inadequate service and supports is not a sustainable model of care. Shifting care into the community will only work when adequate and appropriate community supports are in place. If access to community supports such as respite programs, day programs, employment opportunities, advocacy services, available/quality housing, reliable funding and accessible transportation are inadequate or non-existent, and there is a lack of an available ASD-trained workforce, then the majority of lifelong care will continue to fall to the aging family and the other ways to pay.

If many individuals living with ASD need a range of support over their lifespan and gaps in community support exist, then several questions must be answered: What is a reasonable way to pay for lifelong support? What supports must be in place to provide lifespan quality of life for individuals and families and how can Canadian society better prepare for the current and rising numbers of individuals who will need lifelong support?

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<sup>85</sup> M.E. Dunn et al., "Moderators of stress in parents of children with autism," *Community Mental Health Journal* 37, 1 (2001): 39-52; A. Estes et al., "Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay," *Autism* 13, 4 (2009): 375-387; G. Montes and J. S. Halterman, "Association of childhood autism spectrum disorders and loss of family income," *Pediatrics* 121, 4 (2008): 821-826; C. Sharpley, V. Bitsika and B. Efremidis, "Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism," *Journal of Intellectual and Developmental Disability* 22, 1 (1997): 19-28.

<sup>86</sup> B. J. Myers, V. H. Mackintosh and R. P. Goin-Kochel, "My greatest joy and my greatest heart ache: parents' own words on how raising a child in the autism spectrum affected the lives and their families' lives," *Research in Autism Spectrum Disorders* 3 (2009): 670-684.

<sup>87</sup> L. D. Clyburn et al., "Predicting caregiver burden and depression in Alzheimer's disease," *Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 55, 1 (2000): S2-S13; R. Khanna et al., "Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders," *Journal of Autism and Developmental Disorders* 41 (2010): 1214-1227; R. Schultz and S. R. Beach, "Care giving as a risk factor for mortality: The caregiver health effects study," *Journal of American Medical Association* 282, 23 (1999): 2215-2219.

<sup>88</sup> M. Hines, S. Balandin and L. Togher, "The stories of older parents of adult sons and daughters with autism: A balancing act," *Journal of Applied Research in Intellectual Disabilities*, Doi:10.1111/jar.12063 (2013).

<sup>89</sup> Dillenburg and McKerr, "40 years."

## DISCUSSION

A good quality of life, as outlined in the United Nations Convention on the Rights of Persons with Disabilities,<sup>90</sup> is a concept embraced by most governments and this is apparent in provincial disability acts and disability-access strategies. Unfortunately, when complex care (needed for many across the spectrum) is layered upon unprepared systems, then proper care for the vulnerable is not always a reality.<sup>91</sup> Community care is credible only when measures are in place to ensure that service systems are available and support quality of life for everyone across the spectrum.

One step in understanding the needs is to begin to understand the prevalence by severity. Accurate accounts of ASD prevalence are not available as many older adults have never received a diagnosis. Continuing to work towards a clearer understanding of prevalence and needs will help. To estimate the prevalence in Alberta, we take the population of Alberta, which is approximately 3.6 million, and assume that, at the very least, one person in 100 has an autism diagnosis. The total of individuals living in Alberta with ASD is then approximately 36,000. Based on a report from ASEA,<sup>92</sup> where it was projected that approximately 60 per cent of individuals receiving support from child services in 2012 would not receive funding from adult services in Alberta, likely due to IQ ineligibility, then, at a minimum, there would be 21,600 Persons B and C (with IQ higher than 70) and 14,400 Persons A living in Alberta. These total numbers will be allocated between children, adults and the elderly. Most of the adult Person A individuals with IQ of 70 or below will receive some support from PDD. A portion of the adult Persons B and C receive little to no support but need help based on the Ontario survey of higher-functioning adults needing help in a variety of ways, such as finding and accessing services.<sup>93</sup> Continuing to gather data regarding service-needs and prevalence will be essential to planning for the increasing numbers and demands on stretched services.

### Approaches to Relieve Families

Government initiatives in the form of the annual caregiver tax credit may be considered to acknowledge caregiving as a major public health issue, but if offered as small amounts they do little to impact the substantial amount of support needed for lifelong care. Consider the annual amount of \$300-per-year caregiver tax credit<sup>94</sup> versus \$158,000 a year of care. Unless caregiver tax credits are substantial, they will do little to offset the high costs, and low-income families will be unable to benefit from the design of a non-refundable tax credit.

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<sup>90</sup> United Nations, *Convention on the Rights of Persons With Disabilities*, <http://www.un.org/disabilities/convention/conventionfull.shtml>.

<sup>91</sup> Stoddart et al., "Diversity in Ontario's."

<sup>92</sup> Autism Society of Edmonton Area, *Young lives*.

<sup>93</sup> Of 480 individuals surveyed in Ontario, 50.8 per cent were considered higher-functioning or Aspergers, and only 14.8 per cent had an intellectual disability. Over 60 per cent of this sample needed regular support finding and accessing services (Stoddart et al., "Diversity in Ontario's").

<sup>94</sup> Bruce Campion-Smith, "Caregivers of infirm relatives to get federal tax credit," *Toronto Star*, Oct. 3, 2011, [http://www.thestar.com/news/canada/2011/10/03/caregivers\\_of\\_infirm\\_relatives\\_to\\_get\\_federal\\_tax\\_credit.html](http://www.thestar.com/news/canada/2011/10/03/caregivers_of_infirm_relatives_to_get_federal_tax_credit.html).

The Canadian Registered Disability Savings Plan (RDSP) is a tremendous initiative from the federal government created to assist and encourage families to save for their disabled dependent. Unfortunately, recent data indicates that only 11 per cent<sup>95</sup> of families with disabled dependents have opened an RDSP. If the median after-tax income of a Canadian family without a disability is \$60,000 to \$79,000 per year, and less for those with a disability, and families with ASD dependents also face these additional huge costs of autism related to care, then the purchasing power of the household is much lower for these groups. This means that voluntary tax-sheltered savings vehicles, such as the RDSP, will be of limited impact because of the lack of income available to contribute.<sup>96</sup> It may be that families are unaware of the RDSP benefit; still, many may feel the frustration of living with the burden of high costs and being unable to save for future needs.

### **Targeted Government Enhanced Supports**

There is a need for a supply of ASD-knowledgeable workers that will only become more pronounced at current prevalence rates. With the difficulties in recruiting and retaining qualified staff, and the growing number of adults expected in the coming decade, a critical challenge to the delivery of effective services for adults exists.<sup>97</sup> There is demand, but there are not enough qualified people to fill the demand. Stimulating the market to increase the availability of qualified workers who can help fill roles needed to support individuals with ASD will help. ASD-knowledgeable workers are needed to help fill many roles: in-home and out-of home respite support, group-home care, day-program workers, employment-support coaches and life-skill coaches. These are only a few examples of support-care positions that are needed to assist individuals and families to maintain a good community-based life. With a more available and qualified labour force, quality community care is possible.

Removing the IQ screen for eligibility of services at age 18, which exists in some Canadian provinces, would help those living with ASD who have higher IQ but still lack the functional skills of independence. Investing in the future of those with higher IQ by providing, in some cases, what might be a minimal level of support, could allow them to gain employment and remain independent. New government initiatives in the area of employment will help to support vocational success, but other supports for daily living are still required. From the policy review of website data, one province has addressed the needs of higher-functioning individuals. In Nova Scotia, under the ILS program, a higher-functioning individual can access a maximum of 21 hours a week for support. The ILS support time can be used to help with transportation, grocery shopping, house maintenance and other support-care tasks that enhance an individual's ability to remain independent outside of family supports.

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<sup>95</sup> Tom McFeat, "Disabled ill informed about registered savings plans," CBC News, Dec. 30, 2011, <http://www.cbc.ca/news/business/taxseason/story/2011/12/20/f-rrsp-rdsp-disabilities.html>.

<sup>96</sup> Clarke et al., "A basic annual."

<sup>97</sup> Gerhardt and Lainer, "Addressing the needs."

Governments might consider other models of funding used elsewhere to finance services for individuals in need of support. In the province of Quebec, the government is proposing autonomy insurance as an initiative to address the long-term care needs of the aging population and those with disability. Autonomy insurance<sup>98</sup> is an innovative social project intended to address the increasing demands on services for long-term care in the face of a current system that is complex, inadequate and difficult to access for some. Autonomy insurance will be available to all adults with disability based on their profile of needs and will provide the appropriate level and type of service needed. The autonomy fund will be a protected financial instrument and will be sourced through a variety of ways to give adults with disability the opportunity to freely make choices and receive services that contribute to optimal autonomy over their lifespan.

Government initiatives towards quality housing will be essential in establishing lifelong supports for individuals and families. Models of housing that provide quality services but recognize scale economies can be part of the future solutions. The history of institutions for those with disability is grim, but some of the concepts in terms of economy of scale, if offered in a quality-of-care setting, could be built upon to provide cost-efficient care. The Michener Centre in Alberta is an example of this and was home to a number of high-needs individuals. The closure of this institution was met with mixed emotions for families who considered Michener a sanctuary; an option for when group homes could not meet the high staffing needs for individuals requiring complex care. Some consider the closure as representative of ideology trumping common sense. “Michener is no longer an institution but a place where residents live in homelike settings, enjoying park grounds, on-site pools and occupational therapy.”<sup>99</sup> The Michener Centre had evolved far beyond its institutional roots and offered a safe haven for complex and difficult individuals who could not live anywhere else. Social values around care for those with disability have shifted, but public perceptions regarding “institutions” have not. Seniors with dementia are cared for in facilities that provide a wide range of services and staff: meals are available if needed; group transportation to outings is provided; recreational facilities could be on-site; centralized and standardized staff training and 24-hour staffing with lower ratios at night are available. Good housing models that provide quality supports, community integration, scale economies, and well-supported, trained and paid staff are essential to enhancing quality of life for individuals and families. Group-home settings seem to fall short for some. Alternative models of housing will be important to consider in addressing the growing numbers of individuals in need of supportive housing.

For those who are not eligible for funds in the adult system (such as Persons B or C) the access to supportive housing may not even exist. Again, if done properly, integrated locations for higher-functioning individuals that provide shared transportation, an opportunity for socialization, intermittent emergency help or coaching if needed, and other shared services, are both cost effective and could promote a good quality of life. Housing done right is housing that provides a good quality of life and is cost efficient.

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<sup>98</sup> Government of Quebec, *Autonomy for All: White Paper on the Creation of Autonomy Insurance*, <http://www.autonomie.gouv.qc.ca/documents/livre-blanc-en.pdf>.

<sup>99</sup> Paula Simons, “Michener Centre Closing Poses Heartbreaking Dilemmas. Retrieved from ,” *Edmonton Journal*, May 19, 2013. <http://www.edmontonjournal.com/health/Michener+Centre+closing+poses+heartbreaking+dilemmas/8403261/story.html>

## CONCLUSION

Autism is an expensive condition. Previous cost research may underestimate the total lifetime costs of supportive care and governments may underestimate the high costs needed to provide appropriate community-based quality-of-life supports. Where value gaps exist over the spectrum, families fill in and many struggle, and there exists the possibility of the no-care and substandard-care scenarios. Lifelong support is needed for many living with ASD and the time needed must be provided by someone and paid for in some way. The shift to community care in the absence of appropriate community infrastructure has off-loaded much of the cost of care onto families, especially as individuals age into adulthood. Fragmented policy delivery, lack of lifespan programming, disorganized services, IQ-eligibility issues, challenges finding staff, lack of respite options, and quality-housing shortages are problems that add to the burden on families and individuals who need support. The costs of supportive care must be clearly articulated so that the burden of care is shared in a reasonable and acceptable way between governments and family. Governments must be prepared to adequately support families and individuals, and eventually take on the tasks that ensure a good quality of life for individuals living with neurodevelopmental conditions such as ASD.

## GLOSSARY

**Assessment of Basic Language and Learning Skills (ABLLS):** ABLLS is a comprehensive review of 544 skills for 25 skill areas including language, social interaction, academic and motor skills based on what most typical children acquire.

**Assessment of Functional Living Skills (AFFLS):** AFFLS is comprised of three unique assessment protocols that assess functional, practical and essential skills of everyday life in the areas of basic living, home skills and community participation.

**Autism Spectrum Disorder (ASD):** ASD is a complex, lifelong neurodevelopmental condition. ASD refers to a group of disorders that include autism, Aspergers and atypical autism or pervasive developmental disorder not otherwise specified (PDD-NOS). These disorders share common symptoms such as impaired social interaction, repetitive behaviours, restricted interest and impaired communication.

**Foster Care Placement Scoring Chart (Alberta):** This is a guide to determine the foster parent classification that a child requires to ensure that his or her needs are met. The individual is scored over a number of categories based on three levels of severity.

**Neurodevelopmental conditions:** Neurodevelopmental conditions or disorders are an impairment of the growth and development of the brain or central nervous system. Autism, cerebral palsy and Down syndrome are examples of neurodevelopmental conditions.

**Neurotypical:** Neurotypical is a term used in the autism community as a label for people who are not on the autism spectrum. Specifically, neurotypical people have neurological development and states that are consistent with what most people would perceive as normal, particularly with respect to their ability to process linguistic information and social cues.

**Scales of Independent Behaviour — Revised (SIB-R):** The SIB-R provides a comprehensive assessment of 14 areas of adaptive behaviour and eight areas of problem behaviour.

**Supports Intensity Scale (SIS):** The SIS is designed to measure the amount of support needed for individuals with intellectual disability (ID). The scale has 49 life activities dividing into six main support domains (home-living skills, community living, lifelong learning, employment, health and safety, and social activities) plus supplemental scales to measure needs for protection and advocacy activities, and exceptional medical and behavioural supports.

## APPENDIX A

### NEEDS MAP OF SUPPORTIVE CARE AND COSTS

#### Assumptions Used in the Creation of the Needs Map

- The needs map is an artificial construct and is solely intended to illustrate the variation of needs and estimates of costs for meeting the needs of three unique individuals living with ASD. The needs map was created based on literature reviews and peer reviews with local ASD agencies, clinicians and researchers. ASD as a spectrum condition will most likely be represented by a continuum of needs and costs. In reality, the needs and costs will range from extremely high to nothing depending on the individual level of independence. In the absence of clearly outlined interventions for adults that address the heterogeneity of needs across the spectrum over the lifespan, this estimate of needed supports and costs was considered the best approach to address gaps in support. This approach is similar to research noted in the literature review where journals were used to estimate time logged for support, but differs from that research by taking an approach that describes the heterogeneity of autism.
- Supportive-care tasks needed were considered to be the type of support required, at a minimum, to maintain basic skill levels and assure safety and basic quality of life (access to health care and community integration). The list of supportive-care needs in the needs map were developed from a range of support-assessment tools. This list is not exhaustive as other support tasks could be added to this list (i.e., special diet assistance or alternative therapy implementation). As the list is not exhaustive the costs likely underestimate the full costs of support.
- Our cost-estimate work builds from a report commissioned by Dr. Emery from Brown Economic Consulting Inc., based on information from an occupational therapy report on time to replace the caregiver time that had been provided by the deceased parents of a hypothetical 10-year-old boy with severe autism in Alberta. Brown Economic Consulting used two methods to value that caregiver replacement. One approach values the total caregiving time requirements at market wages, while another “global replacement method” uses the cost of foster care. The Brown Economic Consulting Report uses information based on wages in Alberta and this is reflected in this needs map. Wages used were \$21.43 per hour for awake time (day and evening hours) and \$12.49 per hour for sleep time (night hours). These were the rates for the care required at a Level 2 care scale in the Alberta Foster Care Scoring Chart in Alberta (note: this is not the highest level of care possible). Wages in other provinces may vary and could be as low as \$15 per hour or higher in some provinces.
- Each of the three individuals in Life Stage 1 (age 14–17) attend public school for 190 days of the year for 6.5-hour days. The number of PD days or days off varies in jurisdictions and these hours were based on the Calgary School Board calendar. These hours are time where the education system is responsible to provide supports. These hours of care time are not included in the estimates for value of caregiver time at Life Stage 1, as the individual is supported by the school system during these hours. The authors acknowledge that there are added costs to the school system based on severity and also the likelihood that the parents of special-needs children may have added time requirements to interact with schools. These costs were not factored into the value of caregiver time.



- Level of needs and costs of support over the lifespan are assumed to stay constant. We assume that all three individuals do not improve or deteriorate over their life. This assumption is made because of the lack of clear research defining outcomes for different levels of severity. Some research findings do show better outcomes for higher-functioning individuals, in particular in the areas of employment and relationships; still much is unknown about the outcomes of aging individuals with ASD.
- Costs were calculated in the age bracket of 14 to 17 (adolescence) and 18 to 64 (adulthood). Costs were calculated during these periods of time because these are times when individuals with ASD clearly need supports beyond that of a neurotypical. We assume that neurotypicals begin to need either little to no care-time starting at age 14. In the aging years, starting at age 65, neurotypicals again begin to need support due to aging and government supports are more readily available for those in need. We acknowledge that there will be some caregiver support for a normal 14-year-old (co-ordination of higher-level activities) but costs will be minimal, progressing to none by age 18. When the individual reaches age 65, governments offer services to assist those with unmet care needs. These supports are provided in the form of dementia daycare programs, long-term care or home-care supports; although not ASD specific, they are services provided to meet care-time needs that would be accessible to individuals with ASD.
- The presence of unmanaged challenging behaviours, mental illness and physical health issues may shift care costs upward for all individuals on the spectrum. These problems may increase the need for support in many areas such as: planning for medical appointments, prescription maintenance, supervision of behaviours and interaction with police, and implementation of behavioural-management strategies in particular for individuals who lack the higher-level abilities needed to co-ordinate and manage complex health conditions. A high IQ does not always equate with higher functional ability and less support costs. For example, an individual with high IQ and co-existing anxiety or depression (common in ASD) may display impulsivity, meltdowns, rage, and withdrawal resulting in higher support needs and costs. The impact of these issues on care time is not well researched and for this reason the three individuals in the needs map do not have serious challenging behaviours or co-existing mental or physical health conditions.
- Research in life stages for neurotypical individuals is an evolving field and other life stages could be a possible area for examination as this research continues. For example, a recent article in *Scientific American Mind*, in the January/February 2013 edition, describes “emerging adulthood” as a new, fourth life stage for young neurotypical adults.

## NEEDS MAPS

### PERSON A

Person A represents a severely affected individual with autism spectrum disorder (ASD) with IQ 70 or less (age equivalent of 3–6 years) and who is non-verbal. He struggles with sensory issues and social interaction.

#### LIFESPAN CHARACTERISTICS

**Cognitive:** IQ is untestable due to his cognitive challenges, estimated age equivalent is 3–6 years. Over time and with support is beginning to match letters and recognize numbers. He is unaware of danger (prone to wander and would be unaware if lost). All doors at home have unique lock systems installed that prevent him from opening doors and gates. He can roam inside the house but must be checked every hour as to his activities (razors, stove, sharp objects, and open doors to outside all pose potential hazards).

**Communication:** Non-verbal, uses pictures in a limited way to communicate. Can locate exact picture for items (nouns) but cannot communicate concepts (sick, tired, angry).

**Sensory:** Touch: seeks out deep pressure (squeezing, hugs). Auditory: has low tolerance for noise levels and copes by plugging ears.

**Behavioural:** Behavioural issues include: yelling, occasional mild self-abuse (hitting head), non-compliant behaviours (refusing to stand up, refusing to walk). Behaviours occur when Person A is hungry, sick or unable to communicate his needs. Behavioural strategies work well to manage challenging behaviours.

**Repetitive and Restricted Interests:** Rigid attachment to certain objects requires constant work to enhance his ability to relinquish these objects without behaviours arising.

**Social:** Limited eye contact, uninterested in social contact but will observe others, likes to be around people but no concept of stranger danger.

**Daily Living Skills:** Requires hands-on assistance to complete skills such as brushing teeth, bathing, meal preparation, grocery shopping and cooking.

**NOTE:** *The trajectory for ASD development is unknown. With appropriate programs and supports, Person A could maintain the skills he has gained and continue to learn and move towards independence. Without appropriate supports in place, it is possible that this individual could regress and lose skills, becoming increasingly dependent on others with challenging behaviours that will restrict his ability to participate in employment, community integration, recreation and leisure, thus lowering his quality of life.*

## NEEDS MAP: PERSON A

Life-Stage and Supportive-Care Needs Above a Neurotypical Individual	Annual Hours	Activities of Supportive Caregiver	Gaps
<p style="text-align: center;"><b>Life Stage 1: Ages 14–17</b></p> <p style="text-align: center;"><b>DAYTIME HOURS AND NEEDS</b></p> <p><b>DAY PREP HOURS: 6:30 am–8:30 am</b> Two hours, 365 days of the year = 730 hours of supportive care needed every year, although the actual time may vary on a weekend, but the tasks will not vary aside from school-related prep.</p> <p><b>Supportive-Care Needs:</b> Prompt A out of bed (schedules, sounds, light). He does not understand concepts of time and date; without this communicative understanding he may be uncooperative, or resistant to getting ready for the day. Choose and get weather-appropriate clothing/assist with dressing, get food, oversee eating breakfast, assist with daily grooming and assist with tooth-brushing for him, remind to sit on toilet. On school days, pack lunch for school; organize school bag and clothing. Care provided with a behavioural, communication framework – i.e., using pictures to communicate next steps, managing any behaviours that arise.</p>	<p style="text-align: center;">Day Prep 730 hrs</p>	<p><b>SELF CARE</b> Assistance with daily living tasks from hands-on doing for the individual to partial assistance to do a variety of tasks (bathing, wash hair, brushing teeth, orientate clothing, reminding about toilet, changing soiled clothing, assistance with cutting foods).</p> <p><b>HOME-LIVING TASKS</b> Grocery shopping, cooking, additional laundry tasks due to soiled clothing, he requires full assistance with all tasks partial direction and full supervision will completing tasks.</p> <p><b>SERVICE CO-ORDINATION MANAGEMENT</b> If funded for professional supports or respite there is a co-ordinating function. Co-ordination duties include to hire, train, oversee programs for aides, co-ordinate with behavioural or speech experts, hire, train respite services, oversee payroll, organize team meetings, meet with funding co-ordinator twice a year to confirm care needs. Staff turnover, staff maintenance.</p>	<ul style="list-style-type: none"> <li>· Transition supports.</li> <li>· Reliable and qualified respite workers.</li> <li>· Longer-term and after-school respite workers (especially where difficult behaviours exist).</li> <li>· Funding for behavioural psychologists and speech funding.</li> </ul>
<p><b>TRANSIT HOURS: 8:30 am–9 am and 3:30 pm–4 pm</b> Travel to and from destinations at 0.5 hours each way = one hour x 365 days of the year.</p> <p><b>Supportive-Care Needs:</b> Assuming that each day of the year he will have the opportunity to go out to a destination at least once a day (e.g., school, summer program, recreation, community outing). Safe transport can only be accomplished via supervised walking, supervised public transit, special needs busing or caregiver drives. In transit, caregiver must understand behavioural, communication, social and sensory challenges. In this situation the caregiver drives Person A to school as special-needs busing is not working out.</p>	<p style="text-align: center;">Transit 365 hrs</p>	<p><b>PERSONAL ORGANIZING TASKS</b> Organize all outings, social, recreational events, camps, paperwork needed. Financial-management tasks: finances, banking, and long-term financial planning.</p> <p><b>HEALTH AND SAFETY MANAGEMENT</b> Extraordinary or ASD-specific-related dental and medical care, such as extra dental needs, medication administration, prescription filling, co-ordination of appointments for both physical health and mental health issues such as depression and anxiety, or physical health issues such as increase in seizure disorders. Home-safety monitoring.</p>	<ul style="list-style-type: none"> <li>· Kinship care: Ability to pay for kinship care (siblings or relatives if appropriate and able).</li> </ul>
<p><b>SCHOOL DAYS HOURS: 9 am–3:30 pm</b> School year of 190 days x 6.5 hours a day = 1,235 hours when care is provided by the education system.</p>	<p style="text-align: center;">School Hours 1,235 hrs</p>	<p><b>COMMUNITY LIVING/EMPLOYMENT/RECREATION</b> Co-ordinate and oversee community involvement and volunteer or employment opportunities. Locate job opportunities; work with agencies, job coaching, job maintenance, troubleshooting.</p>	
<p><b>SUMMER DAYS HOURS: 9 am–3:30 pm</b> 30 summer days x 6.5 hours a day = 225 hours.</p>	<p style="text-align: center;">Summer Hours 195 hrs</p>	<p><b>TRANSPORTATION</b> Provide or co-ordinate safe transportation. Requires driving or assistance on public transit. Cannot walk independently.</p>	
<p><b>DAYS OFF HOURS: 9 am–3:30 pm</b> (holidays, weekends, PD days, non-summer days). 145 days off at 6.5 hours a day = 1,087.5 hours.</p> <p><b>Supportive-Care Needs:</b> A neurotypical 14-year-old could by this age hold a job, or stay at home alone for the day and so requires little or no daytime care over summer or PD days. Person A continues to need constant vigilance and structure to his day. Some communities offer summer camps but these are not always available, appropriate or free.</p>	<p style="text-align: center;">Days Off 942.5 hrs</p>	<p><b>ADVOCACY</b> Advocacy if services lacking and/or advocacy to maintain supports (attending meetings, planning, advocating, problem solving). Arranging employment supports and placements. Reviewing new treatment information and implementing therapies that may be beneficial (this could include dietary changes, alternative health strategies or new medications).</p>	

**NEEDS MAP: PERSON A (cont'd)**

Life-Stage and Supportive-Care Needs Above a Neurotypical Individual	Annual Hours	Activities of Supportive Caregiver	Gaps
<p align="center"><b>EVENING HOURS AND NEEDS</b></p> <p><b>EVENING HOURS: 4 pm-9:30 pm</b> 5.5 hours of care x 365 days a year = 2,007.5 hours.</p> <p><b>Supportive-Care Needs:</b> Care provided is a combination of vigilance mixed with tasks of daily living, teaching skills and knowledge of behavioural management and communication techniques. Mealtime needs still require meals prepared and to oversee eating (holds fork, stays on task, cut food for him). Cleaning up after meal with direction of steps. Teaching skills and oversee skills needed around mealtime (load dishwasher). Vigilance is a care task (e.g., check on activities every 30 minutes), can never be left alone. Also reminding re: toileting, appropriate behaviour, working on behavioural challenges (dealing with issues as they arise, and working on developmental strategies to enhance independence).</p> <p>Later evening could be considered more "down time": watching TV, video games, transport to evening activity when needed and supervise activity (bowling, ski, swim), but still requires supervision or hands-on assistance to participate in activities. Bedtime preparations are to assist with bathing (reminding, supervising and competing tasks that are not independent), partial assistance with hair washing, brushing teeth, toileting, prepare room (sheets clean, drapes drawn for darkness, no dangerous items in room).</p>	<p align="center"><b>Evening Hours</b> <b>2,007.5 hrs</b></p>	<p>SOCIAL/COMMUNICATIONS/BEHAVIOUR/SENSORY Teaching social skills. Examples of this for Person A will be to provide supports and teaching that increase: orienting to his name, continued eye contact to request and engage, tolerating noise, asking (via iPad) to leave room when in need of quiet time, understanding concepts of quiet and loud in public places, learning appropriate ways to ask for items, maintaining greetings with a wave, appropriate and inappropriate touching and, for puberty, teaching public and private places.</p> <p>SOME KEY TASKS SPECIFIC TO THIS LIFE STAGE Transition planning and co-ordination to move from youth programs and school system into adult programs. This requires paperwork filled in for all transition to adult programs, funding, and guardianship. Moving into adulthood means leaving the school system, which provided a structured day. Adult programs may be unavailable or inappropriate or unwilling to take highly behavioural individuals, leaving him with no well-structured daytime opportunities. Puberty issues, sexuality and relationships become a key focus at this age. Strategies to teach public and private locations regarding sexuality are essential for Person A. Increased anger, non-compliance, or violence issue may arise due to hormonal changes at puberty.</p>	
<p align="center"><b>NIGHT HOURS AND NEEDS</b></p> <p><b>NIGHT HOURS: 9:30 pm-6:30 am</b> Nine hours x 365 days a year = 3,285 hours</p> <p><b>Supportive-Care Needs:</b> Occasional waking (2-3 times a week for 1-3 hours at a time), not toilet trained at night. Checking at these times to help with toileting or check safety. Person A can never be left alone at night; he may open doors, wander outside or pose a risk to others (e.g., inadvertently turn on gas elements, turn on electrical devices).</p> <p>CALCULATIONS (does not include school hours as provided by public system) DAY/EVENING COST: 4,240 hours x \$21.43/hour = \$90,863.20 NIGHT COSTS: 3,285 x \$12.49/hour= \$41,029.70 \$90,863.2 + \$41,029.7 = \$131,892.90</p>	<p align="center"><b>Night Hours</b> <b>3,285 hrs</b></p>	<p>CAREGIVER REQUIREMENTS: Behavioural-management skills (if behaviours are present), in particular if non-compliant behaviour arises, knowledge and ability to implement unique communication techniques, social-skills teaching, co-ordination and advocacy skills, willingness to provide hands-on care when needed. Meal preparation, assistance with laundry. Male aide is helpful for community outings when individuals are unable to use public toilets independently. Skills to oversee all executive-functioning tasks (managing programs, planning activities, banking and advocacy).</p> <p align="center"><b>ANNUAL VALUE OF CAREGIVER TIME = \$131,893</b></p>	

**NEEDS MAP: PERSON A (cont'd)**

Life-Stage and Supportive-Care Needs Above a Neurotypical Individual	Annual Hours	Activities of Supportive Caregiver	Gaps
<p style="text-align: center;"><b>Life Stage 2: Ages 18–64</b></p> <p><b>SUPPORTIVE-CARE NEEDS IN LIFE STAGE 2</b></p> <p>Key needs after the end of school are to continue to be in an environment that he can maintain the skills he has and continue to learn and grow. Person A will likely still need constant, 24-hour supervision and assistance with daily living and complete care for executive-functioning tasks. School has finished, but there is still a need for structured programming, behavioural and communication supports. Hours covered by the education system are now filled by day programs, where they exist, and if they are appropriate and available. Often the appropriate trained staff and quality structured programs for adults with ASD are difficult to find. Assumption: Quality program and staff exist to replace school days. To simplify calculations we replace school-day hours with adult day-program hours available.</p> <p>CALCULATIONS (add previous hours supplemented by school system)</p> <p>Previous day and evening and night costs = \$131,892.90</p> <p>Add school hours now in need of adult supports (1,235 hours x \$21.43) = \$26,466</p> <p><b>Total: \$131,893 + \$26,466 = \$158,359</b></p>	<p><b>Add in School Hours</b></p> <p>Add in hours previously covered by school: 1,235 hrs</p>	<p>SOME KEY TASKS SPECIFIC TO LIFE STAGE 2: The key tasks remain the same as noted above in the 14–18 category. Lifespan-specific tasks can replace the transition-planning tasks with tasks that focus on estate planning, housing, employment or volunteer and community integration. It could be argued that estate planning should begin at a much younger age, yet in reality, it is likely that many families do not consider this until later in life.</p> <p>CAREGIVER REQUIREMENTS: As above, with emphasis on estate planning, housing, advocacy and provided structured/appropriate day programs.</p> <p style="text-align: center;"><b>ANNUAL VALUE OF CAREGIVER TIME = \$158,359</b></p>	<ul style="list-style-type: none"> <li>· Reliable, qualified, available respite and aid workers.</li> <li>· Respite longer-term in or out of home (more than a few days).</li> <li>· Structured, quality adult day programs.</li> <li>· Vocational, community opportunities.</li> <li>· Funds for behavioural therapists, speech, OT.</li> <li>· Availability of professional supports (e.g., psychiatrists).</li> <li>· Housing options (available, quality).</li> <li>· Lack of primary-care physicians trained in health issues that impact adults with complex developmental disabilities.</li> </ul>

## PERSON B

Person B represents a moderately affected individual with ASD, IQ higher than 70, plus language delay. Person B is verbal but struggles to use language appropriately. He does not understand social cues and context.

### LIFESPAN CHARACTERISTICS

**Cognitive:** IQ = 76, aware of street danger. Levels of independence may increase with appropriate supports as Person B ages. He likely will not be able to fully master higher-level executive functions.

**Communication:** Communicates verbally but has difficulty using his words when needed. He may not speak up when problems arise and may not understand appropriate words to use in novel situations. He requires support and practice to understand appropriate social communication (when to ask questions, what questions to ask, how to respond to questions).

**Sensory:** Does not enjoy noisy settings but has managed to cope by using earphones. He does not like to be touched by others as light touch causes pain.

**Behavioural:** Experiences a high level of anxiety in crowded situations; this leads to inflexible and rigid behaviours. Has limited tolerance for other perspectives and tends to perseverate on certain topics — e.g., trains. He can become angry and unable to control emotions if he is criticized or confronted. Behaviours are not considered severe at this point.

**Repetitive and Restricted Interests:** Perseverance on one topic of interest (trains) causes Person B to want to talk only about trains, to read and research only about train interests.

**Social:** Seeks acceptance from others. Understands he is different than typical. This insight combined with lack of peer acceptance can lead to episodes of depression and anxiety. If there are no meaningful daytime opportunities, he may be prone to isolation and development of anxiety and depression.

**Daily Living Skills:** Is capable of all daily living skills, but needs supports in place and reminders to complete them fully and regularly, as well as supervision, as opposed to hands-on care.

**NOTE:** *The trajectory of ASD development is unknown. Person B has skills, abilities and the focus required to obtain employment and function independently with supports in place. However, keep in mind the challenge of autism in which this individual is unable to use words easily to communicate and does not understand social norms. Without appropriate supports (employment assistance, social-skills training, schedules for independent living) problems with repetitive behaviours may emerge (e.g., perseverating on a topic of interest) and frustration with social expectations can result in behavioural outbursts.*

## NEEDS MAP: PERSON B

Life-Stage and Supportive-Care Needs Above a Neurotypical Individual	Annual Hours	Activities of Supportive Caregiver	Gaps
<p><b>Life Stage 1: Ages 14–17</b></p> <p><b>DAYTIME HOURS AND NEEDS</b></p> <p><b>DAY PREP HOURS: 6:30 am–8:30 am</b> 45 minutes of caregiver time needed 365 days of the year, although the actual time may vary on a weekend, but the tasks will not vary (aside from school-related prep).</p> <p><b>Supportive-Care Needs:</b> Person B needs reminders and supervision for clothing choices for weather and clothing items needed; answer questions about breakfast choices, assist to determine what to eat. Direct to daily living schedule of brushing teeth, washing. Remind to brush all teeth not just one. Show schedule for preparation of school items, lunch, and school bag. Discuss and assist in questions that arise on school issues, questions regarding appropriate communication and management of social situations. No hands-on care needed.</p>	<p>Day Prep 273.7 hrs</p>	<p><b>SELF CARE</b> Reminding to complete daily living activities; may need a written or picture schedule to ensure all steps are completed. Does not require hands-on assistance, but needs reminders with visual schedules and supervision, overseeing with daily living tasks. Complete independence in toileting.</p> <p><b>HOME-LIVING TASKS</b> Grocery shopping, cooking, laundry; is able to assist parent when directed and supervised to follow schedule or steps. Needs a high level of assistance to complete tasks. Direction for appropriate social interaction at grocery store, assistance to cope/understand.</p> <p><b>SERVICE CO-ORDINATION MANAGEMENT</b> If funded for professional supports or respite, there is a co-ordinating function. Co-ordination duties include to hire, train, oversee programs for aides, co-ordinate with behavioural or speech experts, hire, train respite services, oversee payroll, organize team meetings, meet with funding co-ordinator twice a year to confirm care needs. Staff turnover, staff maintenance.</p> <p><b>PERSONAL ORGANIZING TASKS</b> Caregiver must always organize all outings: social, recreational events, camps; paperwork needed. Financial-management tasks: finances, banking, and long-term financial planning.</p> <p><b>HEALTH AND SAFETY MANAGEMENT</b> Care such as extra dental needs, medication administration, prescription filling, and co-ordination of appointments for all health needs. Home safety monitoring is less of an issue for Person B. He is able to remain at home safely at this age for short periods of time (one to two hours).</p>	<ul style="list-style-type: none"> <li>• Transition supports.</li> <li>• Pre-employment opportunities; job coaching.</li> <li>• Funding for behavioural psychologists and speech funding.</li> <li>• Kinship care: Ability to pay for kinship care (siblings or relatives if appropriate and able).</li> <li>• Finding respite care and summer programs to provide support and structure.</li> </ul>
<p><b>TRANSIT HOURS: 8:30 am–9 am and 3:30 pm–4 pm</b> Travel to and from destinations (0.5 hours x 2) but can walk to school; 365 - 190 school days = 275 days = 275 hours.</p> <p><b>Supportive-Care Needs:</b> For the 190 school days, Person B is able to walk to school and requires no care time. He can walk or bike the same route every day but because he cannot drive or take public transit independently (he has difficulty expressing himself and often will not use his words; if something different were to happen on transit – bus breaks down, late, too crowded – he could not cope). Because of this, he must be transported by another. Assume that all other days of the year aside from school (summer, weekends, days off) he will go to one location per day (recreation, social) that requires driving.</p>	<p>Transit 275 hrs</p>	<p><b>PERSONAL ORGANIZING TASKS</b> Caregiver must always organize all outings: social, recreational events, camps; paperwork needed. Financial-management tasks: finances, banking, and long-term financial planning.</p>	
<p><b>SCHOOL DAYS HOURS: 9 am–3:30 pm</b> School year of 190 days x 6.5 hours a day = 1,235 hours.</p>	<p>School Hours 1,235 hrs</p>	<p><b>HEALTH AND SAFETY MANAGEMENT</b> Care such as extra dental needs, medication administration, prescription filling, and co-ordination of appointments for all health needs. Home safety monitoring is less of an issue for Person B. He is able to remain at home safely at this age for short periods of time (one to two hours).</p>	
<p><b>SUMMER DAYS HOURS: 9 am–3:30 pm</b> 30 days over summertime requiring check in/guidance/teaching approximately three to four times during a 6.5-hour period = estimate two hours a day x 30 days = 60 hours.</p>	<p>Summer Hours 60 hrs</p>	<p><b>COMMUNITY LIVING/EMPLOYMENT/RECREATION</b> Co-ordinate community involvement, volunteer or employment opportunities. Locate job opportunities; work with agencies, job coaching, job maintenance, troubleshooting. Is able to remain in community on own for short period of time. (i.e., could attend school function alone or with a friend)</p>	
<p><b>DAYS OFF HOURS: 9 am–3:30 pm</b> (holidays, weekends, PD days, non-summer days). 145 days off. This could be more if Person B is in the higher grades and will have more time off during exam periods. 145 days x 2 hours a day = 290 hours.</p> <p><b>Supportive-Care Needs:</b> Where schedules of day plans change or unexpected changes occur in social situations, Person B may be unable to use the correct words to express his needs; if unmanaged, this may increase anxiety and challenging behaviour. On days off, Person B needs help to co-ordinate his lunches (what to cook, remind how to make). Some summer camps may be available for some weeks where Person B could participate in a camper ratio of 1:6 (not in need of one-on-one care). A neurotypical adolescent at this age could hold a job, or stay at home alone, and so requires no daytime care over summer or days off.</p>	<p>Days Off 290 hrs</p>	<p><b>TRANSPORTATION</b> Provide or co-ordinate safe transportation. May require assistance on public transit; could develop independence on transit with IT supports. Cannot drive a car. Can walk or bike independently to known and short destinations.</p>	

**NEEDS MAP: PERSON B (cont'd)**

Life-Stage and Supportive-Care Needs Above a Neurotypical Individual	Annual Hours	Activities of Supportive Caregiver	Gaps
<p align="center"><b>EVENING HOURS AND NEEDS</b></p> <p><b>EVENING HOURS: 4 pm-9:30 pm</b> 5.5 hours at 20 minutes per hour x 365 = 669 hours.</p> <p><b>Supportive-Care Needs:</b> Person B could safely occupy his time at home without the regular vigilance required for Person A, but he still needs a someone to check-in with regularly, or to be present at certain times (e.g., meal preparation, questions about process, scheduling, safety). For example, Person B could arrive home, open the door and get into the house, however he may forget to shut the door, or if something were to go wrong he would not know what to do (repairman comes to the door, toilet leaking). With schedules and reminders, he would be able to take food from fridge and complete a simple microwave-cooking task, but a properly prepared nutritional meal would require assistance.</p> <p>Teaching skills needed around mealtime (e.g., set table, load dishwasher, choosing nutritional meals) could be done with visual schedules and reminders. During the evening after dinner he needs additional assistance with homework challenges (understanding, reminding, and completing homework). Working with him to cope with frustrations, social-skills, and sensory challenges, dealing with acting-out issues as they arise, and working on developmental strategies to enhance independence and communication ability.</p> <p>Later evening (7 pm-8:30 pm): This could be considered more “down time” – watching TV, video games – and would not need constant supervision. Evening tasks could involve transport to evening activity when needed, but caregiver does not need to fully supervise the activity.</p> <p>Bedtime preparations include supervision of task completion (visual schedules such as hair washing, brushing teeth, reminding of tasks that were missed).</p>	<p>Evening Hours 669 hrs</p>	<p>ADVOCACY Needs support for all educational services (advocacy if services lacking), meetings, planning, advocating, problem solving, employment supports and placements. Transit issues, police.</p> <p>SOCIAL/COMMUNICATIONS/BEHAVIOUR/SENSORY Teaching social skills and communication. Generalizing to all settings may require visual supports, social stories and other strategies. Teaching relationship development, appropriate touching, body changes from puberty, and sexuality issues.</p> <p>SOME KEY TASKS SPECIFIC TO THIS LIFE STAGE Transition planning and co-ordination to move from youth programs and school system into adult programs. This requires paperwork to be filled in for all transition-to-adult programs, funding, and guardianship. Puberty issues, sexuality, relationships become a key focus at this age. Teaching appropriate behaviours in relationships, dealing with increased anger, non-compliance, or violence issues that can arise with hormonal changes at puberty.</p> <p>CAREGIVER REQUIREMENTS: Behavioural-management skills – in particular if non-compliant knowledge – and ability to implement unique communication techniques, social-skills teaching, co-ordination and advocacy skills. No hands-on care required; male caregiver is not required for toileting needs.</p>	
<p align="center"><b>NIGHT HOURS AND NEEDS</b></p> <p><b>NIGHT HOURS: 9:30 pm-6:30 am</b> 9 hours (all night) x 365 days a year = 3,285 hours</p> <p><b>Supportive-Care Needs:</b> No tasks required: if Person B needs a glass of water he can go get it or if he needs to get up at night to use the washroom he is able to do so, but if something were to happen at night (fire alarm goes off, feels sick and needs help, can't sleep) he would not know what to do and so requires an individual to be there. He cannot be left alone at night.</p> <p>CALCULATIONS (does not include school hours as provided by public system) DAY/ EVENING COST: 1,567.7 hours x \$21.43/hour = \$33,595.80 NIGHT COSTS: 3,285 x \$12.49/hour= \$41,029.70 \$33,595.8 + \$41,029.70 = \$74,625.50</p>	<p>Night Hours 3,285 hrs</p>	<p align="center"><b>ANNUAL VALUE OF CAREGIVER TIME = \$74,626</b></p>	



**NEEDS MAP: PERSON B (cont'd)**

Life-Stage and Supportive-Care Needs Above a Neurotypical Individual	Annual Hours	Activities of Supportive Caregiver	Gaps
<p style="text-align: center;"><b>Life Stage 2: Ages 18–64</b></p> <p><b>SUPPORTIVE-CARE NEEDS IN LIFE STAGE 2</b></p> <p>Person B continues to need support plus an appropriate level of daytime structure, employment supports, social-skills training, and communication support. Hours covered by the education system and summer camps are now replaced with higher-education placements (college, university) if available and he is able to attend. Person B will need a portion of supportive-care time during the day hours, whether it is at school or in employment. He has ability to focus and an attention to detail that would make him an excellent worker for the right employer. He would like to become a prep cook but needs supports around teaching social-interaction skills, managing frustration, learning new employment tasks, managing employment strategies and transport to the employment site. He still needs support for all higher-level executive functioning (advocacy, banking, etc.).</p> <p>Estimate of the 1,235 hours of school, or 190 days; each of these days at two hours a day = 380 hours. (380 hours x \$21.43) = \$8,143.40.</p> <p><b>CALCULATIONS</b> (add previous hours supplemented by school system, a portion of these hours) Previous day, evening and night costs = \$74,625.50. Add school hours now in need of adult supports = \$8,143.40. <b>Total: \$74,625.50 + \$8,143.40 = \$82,768.90</b></p>	<p><b>Add in School Hours</b></p> <p>Add in needed hours previously covered by school hours, estimated at two hours in a 6.5-hour period = 380 hrs</p>	<p><b>SOME KEY TASKS SPECIFIC TO THIS LIFE STAGE</b></p> <p>The key tasks remain the same as noted above in the 14- 18 category. Lifespan-specific tasks can replace the transition-planning tasks with tasks that focus on estate planning, housing, employment. It could be argued that estate planning should begin at a much younger age, yet in reality it is likely that many families do not consider this until later in life. Employment supports at this age are critical. Where employment opportunity or supports do not exist this individual is in danger of becoming what one community agency terms “a basement dweller,” or one who could remain alone for some periods of time with no functional or meaningful daytime opportunities. Many live at home for years and in some provinces, because of IQ eligibility, are not able to obtain adult disability funding.</p> <p><b>CAREGIVER REQUIREMENTS:</b> Transporting to work, recreation and social outings. Provide job assistance (finding, interviewing, coaching, maintaining work, transitioning, and employer support). Knowledge in teaching, overseeing, implementing social, communication and behavioural supports and strategies.</p> <p style="text-align: center;"><b>ANNUAL VALUE OF CAREGIVER TIME = \$82,769</b></p>	<ul style="list-style-type: none"> <li>· Housing.</li> <li>· Employment opportunities.</li> <li>· Higher-education placements.</li> <li>· Day Activity (these are the basement dwellers): no place to go during the day, can be left at home alone with occasional phone calls, but cut off from funding because of IQ. Funded supports available that are not dependent on IQ levels.</li> <li>· Social-skills support funding.</li> <li>· Available, ASD-knowledgeable psychiatrists for mental health issues (high levels of depression and anxiety often exist).</li> </ul>

## PERSON C

Person C represents a mildly affected individual on the spectrum living with Asperger syndrome. She has no cognitive delay (IQ in normal range; approximately 100) and no language delay. Her understanding of social norms and relationships is impaired. She has difficulty with organizational tasks (executive-functioning tasks). Costs of supportive care could be higher with the presence of challenging behaviours and co-existing mental and physical health concerns.

### LIFESPAN CHARACTERISTICS

**Cognitive:** Although IQ is approximately 100. Person C still needs assistance with many executive-functioning tasks; in particular, she relies on time-management support systems (checklists, schedules).

**Communication:** Is able to communicate well.

**Sensory:** Touch: Sensitivity to touch. Light touch feels like needles going through body and she must avoid crowded situations. Noise: Too much noise causes extremely painful headaches and increased anxiety. She is often able to cope by using headphones. Visual: Bright lights cause eye pain and headaches.

**Behavioural:** Is prone to episodes of anger but has learned to cope with anger and sensory challenges.

**Repetitive and Restricted Interests:** Person C has an exceptional ability to recall numbers and tends to want to discuss numbers or recall different numbers leading to socially awkward situations. She has developed ways to manage her interest in reciting numbers.

**Social:** Does not easily recognize social cues in communication (body language and facial expressions), which makes learning appropriate social interaction very difficult. The difficulty in recognizing social cues can lead her into vulnerable situations where she can be taken advantage of.

**Daily Living Skills:** Person C has a high level of independence in all daily living, but needs occasional support to be reminded of daily hygiene and appropriate dress for different social situations.

**NOTE:** *The trajectory for ASD development is unknown. Some higher-functioning individuals do attain good outcomes with respect to employment, relationships and independence. However, the interventions or other factors associated with good outcomes for aging adults are not well understood. With appropriate programs and supports Person C may be capable of complete independence, employment, marriage, independent living, recreational events (golfing, running), travelling as finances permit, managing her health-care needs and generally living a good quality of life. Without appropriate supports in place it is also possible that she could lose employment opportunities, becoming increasingly reliant on others to manage finances and housing issues, and become isolated, leading to depression and anxiety.*

## NEEDS MAP: PERSON C

Life-Stage and Supportive-Care Needs Above a Neurotypical Individual	Annual Hours	Activities of Supportive Caregiver	Gaps
<p style="text-align: center;"><b>Life Stage 1: Ages 14–17</b></p> <p style="text-align: center;"><b>DAYTIME HOURS AND NEEDS</b></p> <p><b>DAY PREP HOURS: 6:30 am–8:30 am</b> 20 minutes total x 365 days a year = 121.6 hours of care</p> <p><b>Supportive-Care Needs:</b> Remind to use strategies of day preparation (schedules of shower, clothing, brush teeth, pack school bag). Reminding of time to leave house. Supporting questions or feelings of anxiety that may arise around school or employment. Can independently choose clothing, make breakfast.</p>	Day Prep 121.6 hrs	<p><b>SELF CARE</b> Person C is capable of completing all self-care tasks independently but does not always remember to do so, and at times forgets sequencing and importance of some tasks (e.g., regular hygiene, appropriate dress). She needs reminding, schedules to cope, and teaching.</p> <p><b>HOME-LIVING TASKS</b> She is able to complete laundry, grocery shopping, cooking simple meals, but again requires assistance to help oversee task-management (e.g., is able to microwave a meal, but preparation of more complex meals requires assistance to process and organize).</p>	<ul style="list-style-type: none"> <li>· Support for late diagnosis.</li> <li>· Transition supports to move out of child system into systems that may not fund due to IQ.</li> </ul>
<p><b>TRANSIT HOURS: 8:30 am–9 am and 3:30 pm–4 pm</b> Travel to and from destinations, can walk to school, take public transit, three hours a week (3 x 52) = 156 hours.</p> <p><b>Supportive-Care Needs:</b> Additional time is needed to teach transit skills, travel-transit training (practice different public transit scenarios; coping with noise, crowds, late bus, changing routes). Person C learns to drive a car and additional time is required to teach this skill. She does learn driving skill by age 18. She is able to walk independently to school and eventually is able to take public transit during non-peak hours (avoid crowds and noise). During Stage 1 when she has not yet mastered driving, she will need support to get to locations that are not within walking distance or on a regular public transit route (estimate three hours a week).</p>	Transit 156 hrs	<p><b>SERVICE CO-ORDINATION MANAGEMENT</b> If receiving any government funding, she needs assistance in managing funds and reporting.</p> <p><b>PERSONAL ORGANIZING TASKS – FINANCE</b> Requires support to assist and teach all financial-management tasks and higher-level organizational type of tasks.</p> <p><b>HEALTH AND SAFETY MANAGEMENT</b> Car danger and safety awareness is not an issue, however if behaviours escalate, then safety may be at risk (e.g., anger on public transit may provoke or create violent episodes or involvement of police). Need support to understand social boundaries. All medical, dental, health-related issues require assistance to co-ordinate and oversee. Person C is able to get to a doctor's appointment, express and understand health concerns, but may need strategies or assistance to remind her of medications and oversee complex conditions.</p>	<ul style="list-style-type: none"> <li>· Employment Opportunities.</li> <li>· Coaching for life skills and employment.</li> <li>· Executive functioning assistance (occasional, regular, or emergency).</li> </ul>
<p><b>SCHOOL HOURS: 9 am–3:30 pm</b> 190 school days x 6.5 hours a day = 1,235 hours a day</p>	School Hours 1,235 hrs		
<p><b>SUMMER HOURS: 9 am–3:30 pm</b> 30 summer days at one hour per 6.5-hour day = 30 hours.</p>	Summer Hours 30 hrs		
<p><b>DAYS OFF HOURS: 9 am–3:30 pm</b> (holidays, weekend, PD days). 145 days x one hour of care per day = 145 hours.</p> <p><b>Supportive-Care Needs:</b> Limited summer camps available for higher-functioning individuals. Many would remain at home alone during the day. Supports needed include overseeing meal preparation, teaching nutrition, checking in via phone two or three times a day to assist in planning and problem solving. Being at home if changes in schedules or problems arise in summer or weekends (local pool is closed, friend cancels day out). Estimate two hours of care over a 6.5-hour day in on days off.</p>	Days Off 145 hrs	<p><b>COMMUNITY LIVING/EMPLOYMENT/RECREATION</b> Works in a family-run graphic design business to gain skills. She has excellent computer skills and artistic ability. Time and supports are being allocated to expanding her ability to work outside of a family setting with hopes of offers for other employment. Prefers to do independent recreational activities.</p> <p><b>TRANSPORTATION</b> Relatively independent on transportation if following her set strategies to lessen challenging sensory inputs, and uses coping strategies to manage behaviours. Takes bus and train independently during non-peak hours. Has learned to drive a car. Walks and bikes independently.</p> <p><b>ADVOCACY</b> Coaching for life skills including how to advocate (recognizing when one's integrity or rights are being violated).</p>	

**NEEDS MAP: PERSON C (cont'd)**

Life-Stage and Supportive-Care Needs Above a Neurotypical Individual	Annual Hours	Activities of Supportive Caregiver	Gaps
<p align="center"><b>EVENING HOURS AND NEEDS</b></p> <p><b>EVENING HOURS: 4 pm-9:30 pm</b> One hour each evening x 365 days a year = 365 hours.</p> <p><b>Supportive-Care Needs:</b> Assistance with homework above a neurotypical, problem solving, staying on task, and supporting anxiety or challenges in social experiences from school. Co-ordinate mealtime preparation, instruct or direct Person C in meal tasks (sequence, cooking instructions). Teaching and managing nutrition. Co-ordination of any after-school activities. Reminding of night-time preparation. Estimate two hours over a 5.5-hour period.</p>	<p>Evening Hours 365 hrs</p>	<p>SOCIAL/COMMUNICATIONS/BEHAVIOUR/SENSORY Coaching and strategies for establishing relationships, developing empathy, listening, sharing and collaborating with partner. Important teaching for puberty issues (hygiene, pregnancy, sexual abuse or assault, personal boundaries, recognizing signs of invasion of space).</p> <p>SOME KEY TASKS SPECIFIC TO THIS LIFE STAGE Transition planning and co-ordination, late diagnosis, completing educational requirements, planning for higher education or employment preparations (paperwork filled in for transition to own guardianship). Searching for employment, teaching employment skills. Teaching about puberty issues, sexuality, and relationships becomes a key focus at this age. Person C does eventually get married and needs to understand relationship strategies.</p>	
<p align="center"><b>NIGHT HOURS AND NEEDS</b></p> <p><b>NIGHT HOURS: 9:30 pm-6:30 am</b> Estimate 365 days of the year at two hours each evening = 730 hours</p> <p><b>Supportive-Care Needs:</b> Person C is able to use strategies to calm herself at night. She can independently use the bathroom and get a drink of water. She can make a phone call to friend or to family to ask a question if needed. She needs similar support in adolescence as does a neurotypical 14-year-old, but as she ages she would continue to need access to emergency supports above those of a neurotypical: In cases of roommate disagreements, break-in, fire, unexpected situations where a neurotypical adult could respond but Person C will have difficulty knowing what to do. On average we have allocated one hour a night (although Person C may stay several nights alone but if an emergency arose she might require a series of night supports and assistance to manage).</p> <p>CALCULATIONS (does not include school hours as provided by public system) DAY/ EVENING COST: 817.6 hours x \$21.43/hour = \$17,521 NIGHT COSTS: 730 x \$12.49/hour = \$9,117.70 \$17,521 + \$9,117.70 = \$26,638.70</p>	<p>Night Hours 730 hrs</p>	<p>CAREGIVER REQUIREMENTS: Life Skills Coach and Intermittent Emergency Assistance Supports Person for relationships and employment coaching, coping with sensory challenges and relationship building. Needs executive-functioning assistance (managing finance, co-ordination of programs, troubleshooting problems that arise). Crisis supports at intermittent times by the caregiver must be available to assist in managing unexpected situations (e.g., loss of roommates, loss of job/change job, medical issues).</p> <p><b>ANNUAL VALUE OF CAREGIVER TIME = \$26,639</b></p>	

**NEEDS MAP: PERSON C (cont'd)**

Life-Stage and Supportive-Care Needs Above a Neurotypical Individual	Annual Hours	Activities of Supportive Caregiver	Gaps
<p style="text-align: center;"><b>Life Stage 2: Ages 18–64</b></p> <p><b>SUPPORTIVE-CARE NEEDS IN LIFE STAGE 2</b></p> <p>Person C attends a post-secondary institution for several years and graduates with additional supports to manage the sensory and social challenges she encounters there. Once graduated she is able to obtain employment but requires significant assistance to find, maintain and manage employment. Once she is settled into work she copes well day to day. She has learned to drive a car during day hours (street lights can present sensory challenges preventing her from driving at night). She is able to take public transit, during non-peak hours, independently. She can walk or bike independently. Person C marries, but chooses not to have children. She enjoys a good relationship with her husband and continues receiving support to learn about social and relationship interactions and executive-functioning skills (banking, planning). She enjoys recreational activities such as hiking and cross-country skiing, and prefers these sports over team sports.</p> <p>During unexpected transitions in life or emergency situations she needs phone support, check-in coaching, assistance planning, reminding of new schedules, and supports for executive-functioning tasks. Each day of her life may not require one hour of supportive care but some periods of time may require several days of emergency supports (argument with roommate leaves Person C with no accommodation and caregiver must step in to provide housing or arrange new housing situation) or several hours a week of check-in coaching type of supports.</p> <p>1,235 school day hours = 190 days at one hour a day = 190 hours                      Estimate during the day hours for one hour a day</p> <p><b>CALCULATIONS</b>                      (add previous hours supplemented by school system, a portion of these hours)                      Previous day and evening and night costs = \$26,638.70                      Add school hours now in need of adult supports = 190 hours x \$21.43 = \$4071.70  <b>Total: \$26,639 + \$4071.70 = \$30,710.70</b></p>	<p><b>Daytime hours</b>                      Add in hours previously covered by school at 190 days, approximately one hour per day = 190 hrs</p>	<p>SOME KEY TASKS SPECIFIC TO LIFE STAGE 2:                      TSupport in areas of employment transitions, coping with sensory issues, social and relationship supports, learning executive-functioning tasks (banking, paying bills, house maintenance) will assist her in independent living, developing a relationship, and retaining employment.</p> <p>CAREGIVER REQUIREMENTS:                      Coaching-type roles (life skills, social situations, employment) and crisis supports or transitions and unexpected emergencies.</p> <p style="text-align: center;"><b>ANNUAL VALUE OF CAREGIVER TIME = \$30,711</b></p>	<ul style="list-style-type: none"> <li>· Executive-functioning Role (estate planning).</li> <li>· Supportive Housing Situations.</li> <li>· Crisis Assistance.</li> <li>· Employment Coaching and Life-Skills Coaching.</li> <li>· Primary-care doctors who are trained in ASD.</li> <li>· Available ASD-knowledgeable psychiatrists and psychologists.</li> <li>· Funded supports available that are not dependent on IQ levels.</li> </ul>

## APPENDIX B

### SUMMARY OF POLICY SCAN

Age	Benefit Person A, B, C	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario	Nova Scotia
<b>Children and Youth</b>	A, B, C	Autism Intervention Programs (Ministry of Child and Family Development) \$20,000 per year (under six years of age).  \$6,000 per year (age six to 18).	Family Support for Children with Disability (FSCD) (Ministry of Human Services) \$40,000 per year or more per child (from birth to 18 years).	Autism Early Childhood Therapy Program (Ministry of Social Services) ages three to five = \$25,000 per child.  Cognitive Disability Strategy (CDS), (Ministry of Social Services). Up to \$1,200 per child per month = \$14,400 per year (children up to age 24). The learning component provides \$6,300 to \$12,610 per year per child. It is not clear if this includes funding for respite and other support services.	Applied Behavioural Analysis (ABA) Program (multi-ministry) gives up to \$6,000 per year for home-based portion of ABA program for school-aged children.  Children's Special Services dollar amount not available (covers respite, child development, family supports).	2010-11 Autism Intervention Program (Ministry of Children and Youth Services). All ages up to 18, funds for: autism therapy, support and training to families, school supports, respite services and other supports. 2010-2011 total invested by ministry for children and youth with autism was \$156.9 million. Each year 3,250 families served and 800 children attend ASD camp.	Early Intensive Behavioural Intervention (Ministry of Health). Divided at age four (above age four and below age four). Random selection. \$4 million per year for autism treatment and \$2 million to enhance autism programs.
<b>Adult &gt;18/19</b>	A	Community Living B.C. (Ministry of Social Development) \$46,445 (IQ based).	Persons with Developmental Disabilities (PDD) (Ministry of Human Services) \$48,387 - \$60,000 (IQ based).	CDS (Ministry of Social Services) funds for ASD with no IQ eligibility criteria (ages 18 to 24) Up to \$1,200 per month as above. Plus Community Living Service Delivery (Ministry of Social Services) for adults with DD-IQ eligibility approx. \$30,000 per year average.	Approx. \$50,000; IQ based.	Developmental Services Ontario (DSO) (Ministry of Community and Social Services) application for entry into passport-funded programs. IQ based. Average funding per individual approximately \$50,000.	Approx. \$50,000; IQ based
<b>Adult &gt;18/19</b>	B & C	New initiative, called Personalized Supports Initiative, may provide some support but dollar amounts not found.	Dollar amount not found.	CDS (Ministry of Social Services) funds for ASD specific with no IQ eligibility criteria (ages 18 to 24) Up to \$1,200 per month, dollar amount as above.  Dollar amount not found for over age 24.	Dollar amount not found.	Dollar amount not found.	The ILS program is not IQ based. Individuals can get up to 21 hours a week for independent-living supports.

**SUMMARY OF POLICY SCAN (cont'd)**

Age	Benefit Person A, B, C	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario	Nova Scotia
<b>Income Supports</b>	A, B, C	\$906.42/month	\$1,588/month	\$781 to \$914/month Depending on where you live.	Minimum monthly \$750 (Amounts are not available on the website according to ministry staff. Standard amount for minimum obtained verbally from staff at Manitoba Family Services and Labour).	\$1,053/month	\$773/month
<b>Per single individual per month</b>							
<b>Notable Initiatives</b>	Impact A, B, C or ALL	Transition Protocol (six ministerial initiatives) ALL  Personalized Supports Initiative (adults) = B, C	Most generous income supports program = ALL  Well-funded child and youth disability supports = ALL	Cognitive Disability Strategy = ALL  Framework and Action plan/ASD = ALL	Thrive Autism Strategy = ALL  Provincial Caregiver Tax Credit = ALL  Provincial Caregiver Act = ALL	Provincial Respite Network = ALL	ILS Program = B, C  Project Lifesaver = ALL

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