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The University of Calgary is home to scholars in 16 faculties (offering more than 80 academic programs) and 36 Research Institutes and Centres including *The School of Public Policy*. Founded by Jack Mintz, President's Fellow, and supported by more than 100 academics and researchers, the work of The School of Public Policy and its students contributes to a more meaningful and informed public debate on fiscal, social, energy, environmental and international issues to improve Canada's and Alberta's economic and social performance.

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

WHY IS THIS AN IMPORTANT ISSUE?

An estimated 1 in 86 children are diagnosed with Autism Spectrum Disorder (ASD)¹ making it the most commonly diagnosed childhood neurological condition in Canada.² The true costs of lifelong support for people living with ASD³ are often underestimated and fail to acknowledge the value of caregiver time over the lifespan. Significant gaps in publically provided support systems leave the cost burden to be picked up by families. Relying on continued family supports where community services are fragmented or unavailable is not a sustainable approach.

WHAT DOES THE RESEARCH TELL US?

A continuum of supports are needed

Most people living with ASD need supports that range from occasional assistance with higher level tasks, like organizing appointments or banking, to those who need continuous help with daily living.⁴ Areas where supportive care may be needed can be categorized broadly to include: self care, home living, service co-ordination, personal organization, health and safety management, adult day opportunities/employment, transportation, advocacy and social skills. These supports are most successful when they address the individual's uniqueness in terms of communication, social, sensory, behavioural needs and physical and/or mental health conditions. Currently there are a lack of available supports, limiting opportunities for socialization, employment and residential living resulting in reduced independence for adults with ASD.^{5,6}

The true costs of care are underestimated

The lifetime costs for an individual with ASD ranges from \$1.2 million to \$4.7 million.^{7, 8} However these estimates do not reflect the cost of caregiver time. We estimate the cost of caregiver time supporting adults with ASD range from \$30,711 to \$158,000 per year. For individuals with ASD requiring constant support, 24 hours a day, the lifetime caregiving cost is estimated at \$5.5 million, above the costs of care for a neurotypical individual. This means an ASD 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 (that amount does not even account for added professional services or additional out-of-pocket expenses that may be required). Few Canadian families have this level of income.

Families use a variety of ways to pay for care for individuals with ASD who need support, including a mix of government funding, private funding/philanthropy, out-of-pocket funding and self-provision of care. Insufficient funding results in inadequate or no care. Lifelong family caregiving is extremely stressful and can be financially devastating. Families often suffer the emotional, social and financial consequences.⁹

Gaps in policy and programing exist across provinces

A scan of provincial policies finds a patchwork of unequal and incomplete supports. Gaps are especially evident once individuals leave the public school into adult support systems that are inadequate, and in provinces where IQ scores are used to determine service eligibility. Federal initiatives like the RDSP and caregiver tax credits, although recognizing the economic impact on families, have limitations. Promising provincial policy includes: Alberta's Assured Income for the Severely Handicapped (AISH) basic level income support program, cross ministry strategies in Saskatchewan, Manitoba and BC to improve access to resources and supports, the Independent Living Supports Program in Nova Scotia¹⁰ and the Autonomy Insurance Program in Quebec.^{11, 12}

WHAT ARE THE NEXT STEPS?

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. The complete value of caregiver time report and full recommendations can be accessed at <http://www.policyschool.ca/wp-content/uploads/2016/01/Emery-Autism-Costs.pdf>.

Where gaps exist, families fill in, and many struggle. Some key recommendations for improvement include:

1. Develop financial services that better serve the needs of families

Federal and provincial initiatives in the form of caregiver tax credits acknowledge the importance of caregivers but when given in small amounts do little to offset lifelong costs. The Registered Disability Savings Plan (RDSP) is an effective federal initiative to help families, however very few families have contributed, likely due to lack of awareness or inability to contribute. Government should examine and address these issues to improve contribution rates. Other innovative financial support models should be explored, such as the Quebec insurance initiative 'Autonomy for All' with the intention to ensure adults with disability receive quality lifelong care.

2. Implement programs to incent growth of an ASD-knowledgeable work force

Incentives or recruitment programs are needed to increase the availability of qualified and well-paid support staff. ASD-knowledgeable workers help fill many roles such as in-home and out-of-home respite support, group-home care, day-program workers, employment-support coaches and life-skill coaches. Currently there are limited adult service providers trained in specialized ASD support needs and wait lists for programs. Ineffective services and a lack of qualified staff result in reduced opportunity for community access, recreational activities, post-secondary program access and employment.¹³ Incentive or training programs such as the Manitoba University based autism-specific training programs to enhance recruitment strategies are needed to overcome difficulties in recruiting, retention and training of qualified staff noted in research on support need for adults with ASD.¹⁴

3. Remove the IQ score for adults on eligibility for funding

Some provinces have an IQ screen that makes adults with ASD with higher IQ ineligible for services.¹⁵ Provinces should strive to create a system that recognizes level of functional ability and need. Provision of minimal level of support to those living with ASD who have higher IQ but may need assistance with things like transportation or groceries, could allow these individuals to gain employment and remain independent.¹⁶

4. Develop quality housing that is cost-effective, sustainable and safe

Adults with ASD and their families face a housing crisis which exists across many provinces. Group homes fall short for many and other options may be inaccessible, as they require exceptional parental contributions in time and finance to be realized. 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.

5. Support research for best practice

Research regarding service needs and prevalence will be essential to planning for the increasing numbers and demands on already stretched services. Key areas of focus include: the impact of mental health and other co-morbid conditions on service needs, effective intervention programs for adults,¹⁷ methods for increasing training and retention of ASD-knowledgeable workers¹⁸ and experiences of aging caregivers of adults living with ASD.¹⁹

Notes

1. Lowe, Dudley, Dutton, Zwicker, McMorris, Emery, Nicholas and Clarke, "Laying the Foundation for policy: Measuring local prevalence for autism spectrum disorder", The School of Public Policy, University of Calgary. *SPP Research Papers*, Vol. 7 (28), September 2014.
2. Fombonne, "Epidemiology of pervasive developmental disorders," *Pediatric Research* 65 (6), 2009: 591-598.
3. Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition marked by impaired social interaction, repetitive behaviours, restricted interests and impaired communication.
4. Stoddart et al, 2013.
5. Autism Edmonton. Young Lives, Bright Futures?; Autism Calgary, Adult life with Autism.
6. J. E. Graetz, "Autism grows up: opportunities for adult with autism," *Disability and Society* 25, 1 (2010): 33-47.
7. Amendah et al., 'The Economic Costs.'
8. Ganz, 2007. High financial costs are due to direct medical costs (services), non-direct costs or out-of-pocket costs (special education, child care), and indirect costs (lost employment opportunities for both the individual and the parent).
9. Dunn et al., 2001.; Myers et al., 2009; Hines et al., 2013.
10. Provides up to 21 hours of support services per year to those in need (eligibility was not based on IQ score).
11. An innovative social project suggesting an insurance based plan that provides services to all adults with disability throughout their lifespan based on level of need.
12. Dudley and Emery, 2014.
13. Autism Society of Edmonton Area, Young lives, bright futures? (2007).
14. Gerhardt and Lainer, "Addressing the needs."
15. Dudley and Emery, 2014.
16. Nova Scotia has a model for this with the Independent Living Supports program where a higher-functioning individual can access a maximum of 21 hours a week for support with support-care tasks that enhance an individual's ability to remain independent outside of family supports.
17. P. T. Shattuck et al., "Services for adults with an Autism Spectrum Disorder," *Canadian Journal of Psychiatry* 57, 5 (2012): 284-291
18. 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.
19. 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).