



Workers with ASD on the job at a bakery and catering co-op in Toronto, where they are shareholders in the business. Photo courtesy of Kelly Brothers Productions and the Sinneave Family Foundation—from the documentary *Autism Grows Up*.

# Opportunity and Success

## FOR YOUTH AND ADULTS WITH AUTISM SPECTRUM DISORDER

Margaret E. Clarke, David B. Nicholas,  
Herb Emery and Carolyn Dudley

*Canadians with Autism Spectrum Disorder (ASD) will benefit from the vocational initiatives announced by the Harper government in the 2014 budget. Underemployment, unemployment, family financial burden and poor adult quality of life are a reality for many living with ASD. CommunityWorks Canada is an innovative concept for supporting youth with ASD (12 to 24 years of age) and their communities for increased vocational opportunity. Employment policy initiatives along with quality housing options and caregiver supports could highlight Canada as an international leader addressing solutions for those with neurodevelopmental conditions like ASD.*

The February budget speech of Finance Minister Jim Flaherty was remarkable for Canadians affected by Autism Spectrum Disorder for two reasons. First, ASD was specifically identified as a condition that was to be supported by the commitment of \$26.4 million over four years to support increased employment and labour force participation of affected individuals. Second, the announced funding was for adults with ASD, where much of the policy focus on ASD to date in Canada has been on early intervention for children. Prior to this announcement, there has been a “support cliff” for persons with ASD who transitioned from adolescence to adulthood.

It is perhaps not surprising that ASD has been prominently addressed, as it is now the most commonly diagnosed neurodevelopmental condition

in children. Prevalence rates indicate that one in 88 children is now diagnosed on the spectrum.

ASD is one of society's most costly neurodevelopmental conditions. Research shows that families experience added financial burden due to the loss of employment opportunities for the individual living with ASD, the loss of parental employment opportunities due to caregiver time redirected for support, and the added costs associated with having a disability, such as speech therapists, occupational therapists, psychologists and special equipment or other resources. Many individuals living with ASD need lifelong support and incur extensive costs to obtain needed support. The value of caregiver time for a high needs individual are at least \$158,000 per year, amounting to \$5.5 million over a lifetime, above the costs to support a neurotypical individual.

Some of the high economic burden associated with ASD arises from poor labour market opportunities. Canadians with ASD, along with other neurodevelopmental conditions, have extremely low labour force participation rates at around 44 per cent, and employment rates of around 35 per cent. Even when these individuals have employment they are unlikely to work full time. Canadians with physical disabilities fare much better in the Canadian labour market even though they are typically much older.

Preliminary findings from a review of vocational services for persons with ASD suggest that parents often shoulder the burden to create and maintain vocational opportunities for their adult children. Participants identified employment barriers in the form of negative societal attitudes in the workplace, lack of effective supports and difficulty with workplace transitions. Negative workplace experiences can lower confidence in one's employment ability and pose barriers to successful employment in the present and future.

With effective policy interventions, labour market outcomes can be improved. Numerous examples from coast to coast illustrate that when vocational capacity, access and support are in place, employment opportunity and stability can be nurtured. Figure 1 reflects findings emerging from a national study by Canadian researchers

## ASD is one of society's most costly neurodevelopmental conditions. Research shows that families experience added financial burden due to the loss of employment opportunities for the individual living with ASD, the loss of parental employment opportunities due to caregiver time redirected for support, and the added costs associated with having a disability.

at the University of Calgary, University of Alberta, University of Toronto, University of British Columbia, and Dalhousie University, as well as leaders in ASD organizations. The figure outlines elements contributing to vocational success for individuals with ASD: (i) individual preparation and support, (ii) pro-employment policy and programming, (iii) engagement and supports for employers, and (iv) community capacity and a commitment to inclusive employment. Based on emerging evidence, these factors nurture positive outcomes for employees with ASD and favourable "bottom line" outcomes for employers. As these elements are increasingly integrated in the Canadian marketplace, we anticipate that increased job stability can be achieved for persons with ASD.

In the 2014 budget the government is committing to support two complementary initiatives—Ready, Willing and Able (\$15 million over three years) and *CommunityWorks* Canada (\$11.4 million over four years). These programs align with the findings and recommendations of the Federal Panel on Labour Market Opportunities for Persons with Disabilities. These initiatives can assist those

who have the skills to obtain viable employment and secure jobs that may elevate them out of a life of poverty and engage the employment sector to realize the vast potential contribution of persons with disability in the Canadian labour market.

*CommunityWorks* Canada, a partnership between the Sinneave Family Foundation and Autism Speaks Canada, offers a model of community-based employment engagement for youth and young adults with ASD age 12 to 24 years. Participants are exposed to and supported in the workplace at an early age, along with an integrated program of focused training, community engagement and nurturing relationships. Individuals with ASD are paired with neurotypical peer mentors who mutually learn, practice and apply job skills. Within community placements, participants are coached and supported in workplace strategies that ultimately foster employment success. Outcomes from a pilot in the US have shown multiple gains for participants in work related skills such as problem solving, task focus and social interaction.

Two ingredients to successful employment for persons with ASD have emerged. First, early vocational exposure offers opportunity for skill devel-

FIGURE 1: Elements Contributing to Vocational Success in ASD



opment, practice and determination of optimal job “fit” as well as community awareness of the contribution of persons with ASD. The experience of working in the community reflects youth access to various work settings such as food banks, libraries, food services, offices, etc. Beyond structured opportunities for work, training and practice gained by the individual with ASD and peer, additional benefits are anticipated that reflect employer, co-worker and community awareness, ideally promoting a deeper ‘welcoming’ via relationship building and greater realization of strengths and contributions.

Second, vocational success entails the integration of services such as job coaching, life skills development and employer training. This training, support, nurturing and community capacity offered by *CommunityWorks Canada* has demonstrated substantial impact, with anticipated outcomes of heightened labour market inclusion

**The opportunity to work will provide meaning, purpose and structure for Canadians affected by ASD through social engagement, meaningful contribution, engagement and acceptance. Initiatives like these offer hope for improved life conditions.**

for people with ASD. Participating sites across Canada will be supported in capacity enhancement within their respective community, and extensive evaluation is planned for ongoing program improvement.

Based on projections for scalability and impact, we anticipate that approximately 1,200 youth with ASD will benefit each year once the initiative is scaled to capacity. Key components of

the initiative are outlined in Table 1.

TABLE 1 KEY PROGRAM COMPONENTS
Relationship with an individual with ASD and a peer in a series of job preparation opportunities
Participation in two volunteer placements
Summer co-op placement in varied settings—libraries, food banks, social enterprises, etc.
Curriculum ‘toolkit’ development with technology supports to maximize independence
Regional adaptation for region-sensitive application
Education and development in schools and community organizations
Engagement of participants, peer mentors and university/college student coaches
Facilitator and mentor training
Monitoring of program initiation
Program evaluation
Capacity development within and across regions

*CommunityWorks Canada* complements the “Ready, Willing and Able” program that is being led by the Canadian Association for Community Living (CACL) and the Canadian Autism Spectrum Disorders Alliance (CASDA). Where *CommunityWorks Canada* prepares youth for employment success in adulthood, Ready, Willing and Able offers preparatory and developmental steps in moving toward employment (see Figure 2).

**T**he opportunity to work will provide meaning, purpose and structure for Canadians affected

by ASD through social engagement, meaningful contribution, engagement and acceptance. Initiatives like these offer hope for improved life conditions. Enhancing vocational supports vicariously also has the potential to lessen financial burden on the Canadian tax base, support families, and importantly promote better quality of life for individuals with ASD and other developmental disabilities.

Vocational supports are a good start, but a comprehensive plan to address the unmet needs of this growing demographic is still needed. Quality housing models, caregiver supports, accessible health and mental health resources, along with vocational opportunities, addressed together, will begin to form a strategy with significant impact. To that end, the 2014 budget is an important step forward, but still lacks a more aggressive approach to addressing the growing needs of aging Canadians and individuals with neurodevelopmental conditions who need a broad range of lifelong support.

Canada could be an international leader in policy that addresses the needs of those with neurodevelopmental conditions, if the vision for vocational opportunity is coupled with other needed initiatives. Addressing the spectrum of challenges and needs makes sense for the Canadian economy and the health and well-being of individuals and families. To that end, the introduction of *CommunityWorks Canada* and Ready, Willing and Able constitute important steps forward. **P**

*Margaret Clarke is a professor in the Department of Pediatrics at the University of Calgary and Senior Vice President of the Sinneave Family Foundation.*

[margaret.clarke@sinneavefoundation.org](mailto:margaret.clarke@sinneavefoundation.org)

*David Nicholas is an associate professor at the University of Calgary, specializing on issues of transition into adulthood and vocational strategies for individuals living with ASD.*

*Herb Emery is a professor of economics, and Director of Health Policy, School of Public Policy, University of Calgary.*

*Carolyn Dudley is a research associate at the School of Public Policy, University of Calgary with a research focus on lifespan needs for individuals living with ASD.*

[cdudley@ucalgary.ca](mailto:cdudley@ucalgary.ca)

**FIGURE 2: Relationship between *CommunityWorks Canada* and Ready, Willing and Able**

COMMUNITYWORKS CANADA	READY, WILLING AND ABLE
→ Capacity building	→ Focused on employer demand side
→ Preparation for employment	→ Employee and employer preparedness and support
→ Peer mentorship	
→ Community building	
→ “Roadmap” preparation for present and future success in “Ready, Willing and Able”	