



Report on the Professional Issue Forum on “Services for people on the autism spectrum disorder across Canada: Initial step to mapping a shared voice”

CAOT Virtual 2020

Professional Issue Forums (PIFs) are held annually at the Canadian Association of Occupational Therapists (CAOT) conference. PIFs address priority health and social issues, as well as emerging practice areas in occupational therapy. PIFs involve presentations from a panel of experts, and participants are invited to contribute their perspectives. The discussion leads to recommendations for CAOT, individual occupational therapists, and stakeholders to act to advance occupational therapy practice and the profession’s presence in these areas.

The PIF addressing services for people on the autism spectrum disorder (autism) was organized and coordinated by Julie Lapointe, director of knowledge translation at CAOT, and facilitated by Dr. Michèle Hébert, lead panelist. It was held virtually on May 7, 2020, during the first-ever online national conference. The forum was held on the Zoom platform and consisted of short presentations by three panelists/experts in the field, with integrated periods of stakeholder engagement opportunities throughout the session. Stakeholder perspectives were collected via a survey using Mentimeter (an online interactive presentation application) and the Zoom chat box. Participants included professionals, student occupational therapists, and people with lived experience, that is, people on the autism spectrum and/or relatives/families of such persons (*Autism-P*). This report will provide an expanded summary of the presentation and an analysis of the data collected by the participants.

Introduction

At least one in 66 children in Canada from the ages five to 17 years is diagnosed with autism (Public Health Agency of Canada, 2018). At 18 or 19 years of age, children and families lose their pediatric care providers, as the majority of programs target the early childhood and school-age phases, with far less support being available for youths transitioning to adulthood or for adults. Occupational therapy ranked second to speech-language pathology as the most frequently provided service for *Autism-P* (Interactive Autism Network, 2008), highlighting strategic opportunities to serve this population.

Some provincial or territorial programs may be accessed based on a child’s needs, while other such programs require a diagnosis of autism to be eligible for services. Across provinces and territories, annual funding limits range from \$4,000 to \$26,000, and hours of available weekly early intensive treatment range from 15 to 30. Funding and access to services, including occupational therapy services, for *Autism-P* are inconsistent, sparse, and found by parents to be largely suboptimal in Canada (Dangerfield, 2009; Weiss et al., 2014).

Objectives

The objectives of this PIF were to:

- Begin co-creating a shared occupational therapy vision over the next five years targeting four audiences: occupational therapists, people with autism, colleagues in other health professions, and policy makers
- Identify practice resources that are required to realize a shared vision
- Collect enriched perspectives of occupational therapy services across the country
- Define the ideal positioning of occupational therapy in the continuum of care for *Autism-P*
- Propose key advocacy actions for individual occupational therapists and CAOT

A total of 57 participants from eight provinces/territories across the country attended the forum, including practicing occupational therapists and student occupational therapists. Over a quarter (26%) of the participants were people with lived experience. Occupational therapists in attendance reported offering services to clients of almost all age groups, except infants, and working in diverse settings, including clinical, academic, regulatory, and promotional.

Panel Presentations

The first presenter, Dr. Michèle Hébert, PhD, OT, is a postdoctoral scholar in the School of Public Policy and the Faculty of Social Work at the University of Calgary, as well as founder and chair of Buds in Bloom, a nonprofit organization serving children/youths with disabilities and their families.

Dr. Hébert began her presentation by addressing that today, having a diagnosis of autism remains the eligibility criterion and entry point to receiving most interventions and accessing government services. An early diagnosis is optimal and does not solely mean receiving a diagnosis at a young age, but also encompasses receiving a timely diagnosis later in life, when suspicions or signs emerge. Making the distinction between autism and sensory processing disorder, anxiety, and/or depression, for example, remains a diagnostic challenge requiring interprofessional collaboration. A trained occupational therapist can contribute to the developmental screening of autism, and in several clinics across Canada, one is relied upon to inform an autism diagnosis.

Dr. Hébert then gave an overview of evidence-based practice in this area throughout the lifespan, from infancy to older age, referring in part to Wong and colleagues' review of interventions (2015). She explained that there is an abundance of literature on autism in early childhood, and a number of researchers have demonstrated improved autism trajectories following the use of early interventions, such as the Early Start Denver Model (Dawson et al., 2010; Rogers & Dawson, 2009; Rogers et al., 2012), Social ABCs (Brian et al., 2016, 2017), and Autism Navigator (Wetherby et al., 2014). These interventions integrate parent coaching approaches that are designed for infancy through toddlerhood, and they are a natural fit for clinical occupational therapists. However, an occupational therapist typically spends about one

hour per week with a child or parent, so Dr. Hébert asked attendees to reflect on “What is the value that we can bring in that one hour?”

The literature related to childhood and adolescence was summarized and an important gap was highlighted: the pediatric-to-adult transition. Emphasis was placed on the importance of preparing for a transition from pediatric to adult care. With teens’ increased motivation for independence comes heightened risk for anxiety/depression in both youths with autism and caregivers. The emergence of additional occupations during this stage such as driving, independent living apart from one’s parents, and employment were also touched on. Available occupational therapy services can have a range of focuses, including socialization training, independence in everyday living, and safety and self-management.

In explaining the challenges faced by this age group, Dr. Hébert shared a story presented through video that referred to this transition moment as the “supports cliff” (BC Children’s Hospital, 2020). The cliff represents the transition from pediatric care to adult care, as if the youth transitioning is on the edge of a canyon and must cross the bridge, but the bridge is broken (<https://www.youtube.com/watch?v=INiYst1yGIM>). The story illustrated that this individual may be provided with tools but has to figure out a way to cross all on their own with nobody waiting on the other side. Dr. Hébert also mentioned the challenges both for such individuals and for caregivers of youths and young adults on the spectrum moving out. Many parents may not be emotionally ready for this step and may inadvertently enable helplessness in their child. Therefore, parent support groups are useful to foster family occupational independence.

Next, Dr. Hébert illuminated that, as of now, the state of research regarding adults with autism is “a bit like a big black hole.” One group is developing vocational training/employment readiness programs across Canada to improve the reality that the majority of adults with autism (83% of surveyed respondents) reported no employment income (Worktopia, 2012). Wong and colleagues (2015) presented a matrix depicting evidence-based interventions by age group from childhood to early adulthood. In the older adult population, the trajectory of cognitive function differs between those with and without autism (Geurts & Vissers, 2012). Housing is an area of need at this stage. End-of-life care and mental health interventions, such as anxiety management and prevention of depression, may also grow in importance in this age group.

To incorporate a systems perspective, Dr. Hébert then defined coordinated care as seamless and integrated care across borders, systems, and organizations—an area of need for *Autisms-P* as breakdowns can occur between hospitals, community providers, and the home (Matthews et al., 2020). This fragmentation leaves *Autism-P* with heightened burden of care coordination, lower quality of life, and increased expenses (Hodgetts et al., 2015). Bronfenbrenner’s (2009) ecological systems model was used to represent the child/youth/adult with autism within a broader, multisystems societal context—from microsystem, representing the environment immediately interacting with the child/youth/adult, to chronosystem, representing changing trends and beliefs over the life course. An example given of a changing trend is the increase in

virtual connection opportunities in the last thirty years since the advent of the internet age—an instrumental trend in a time of imposed physical distancing such as the COVID-19 context. Luke and colleagues (2018) created an environmental scan of pediatric navigation systems across Canada for medical complexities and mental health issues; however, virtually absent was a focus on navigation programs for *Autism-P*. Dr. Hébert included a powerful visual of a systems map representing what *Autism-P* might have to navigate to get help, including health, education, legal, and financial services (Lind, 2012). This map provided a powerful tool for reflecting on how occupational therapy might assist clients in this maze of seeking, finding, and accessing supports and care.

Dr. Hébert concluded by articulating the shared goal of finding the links in the system chain that are missing and determining how they can be filled and strengthened through the use of an occupation-based lens. Occupational therapy is positioned to support *Autism-P* across the life care continuum, and occupational therapists can use an understanding of meaningful occupations to strengthen supports for autism and facilitate family occupational independence.

Louise Burridge, the second presenter, is an occupational therapist who holds a master's degree in educational psychology. Over her 20-year career, she has worked in hospitals, schools, and the ministry of education, and she currently owns a private occupational therapy clinic in Regina. Her passion is exploring ways to enhance services through online technology.

Ms. Burridge provided an overview of research outcomes for youths and adults with autism. While the body of available evidence is growing, findings remain inconsistent and are often conflicting. Considerable investment has gone into program development, yet outcomes remain relatively poor for relationships, independent living, and mental health (Dudley et al., 2015). Additionally challenging is the lack of agreement on how such outcomes should be measured or what constitutes improvement. Moreover, *Autism-P* have the lowest rate of employment in comparison to individuals with other disabilities. Research indicates that only 6% of *Autism-P* are competitively employed, and over 50% of youths with autism remain unemployed two years following high school completion (Shattuck et al., 2012). The majority of those who are employed endure extended periods of joblessness and frequently shuffle between positions. Unfavourable employment outcomes result in lower quality of life and steep economic costs (Dudley et al., 2015). Despite these findings, paid employment opportunities improve quality of life, cognitive functioning, independent living, and community participation (Joshi et al., 2012; Walsh et al., 2014), as well as facilitate economic self-sufficiency, increased self-esteem, and financial security (Joshi et al., 2012).

There are two significant areas that predict long-term outcomes for *Autism-P*: independence with adaptive living skills and level of executive functioning, including aspects such as working memory, flexible thinking, and inhibition of responses. Not surprisingly, both areas are in the realm of occupational therapy (Bishop-Fitzpatrick et al., 2016). Ms. Burridge explained eight predictors of post-school success for *Autism-P*, including: collaborative networks of agencies involved in team meetings; a strengths-based approach to individualized career development plans; community-based work experience as a youth; social skills instruction within natural

environments; support for the client's self-determination and autonomy; and supportive parental involvement and expectations for future success.

According to Ms. Burrige, governments are wise to pay attention to employment outcomes in youths/adults with autism, as the rising numbers of children diagnosed will age and have unique strengths and abilities that are advantageous to the community and workforce. Occupational therapy provides opportunities to improve outcomes for *Autism-P* by optimizing the person-occupation-environment fit (Law, 1996) and, in turn, facilitating better quality of life.

Jonathan Lai, MSc, PhD, the director of strategy and operations at the Canadian Autism Spectrum Disorder Alliance (CASDA), was the final presenter. In this role with CASDA, Dr. Lai coordinates stakeholders to guide the development of a National Autism Strategy.

Dr. Lai spoke of national and international advocacy around autism from the perspective of CASDA. Founded in 2008, CASDA is an alliance of organizations and individuals working to support autism services. Its mission is to ensure the creation and implementation of a comprehensive National Autism Strategy that addresses critical gaps in funding and policies, which are preventing *Autism-P* from exercising their equal rights as Canadians.

Dr. Lai showed that, based on the work of Bullock and Abelson (2019), federal action was ripe for the National Autism Strategy as three strategic components were present: 1) identification of stakeholder needs, 2) stakeholder consultation and prioritization, and 3) presentation of policy options/alternatives. This strategy was first achieved through a 2014 CASDA needs assessment survey that sought to improve understanding of the priority needs of *Autism-P* across the lifespan. Based on this research, reports identified predictors of service needs and unmet needs, as well as specific services received. Results indicated that as individuals age, they are less likely to have their priority needs met based on the services they are receiving (Lai & Weiss, 2017).

In 2019, a blueprint of an autism strategy was created by CASDA to meet the prioritization of needs. This blueprint recommended three ways the federal government can provide leadership and five immediate areas for federal action. In 2019, Prime Minister Justin Trudeau announced an endorsement for the development of a national autism strategy, committing to acting on it during the government's term in office. More details can be found in CASDA's April 2020 webinar titled *From Blueprint to Roadmap* (CASDA, 2020).

CASDA has created working groups to guide policy development in each of the five federal action areas in which the government is to take specific action. Parallel to this, CASDA is working with various professional groups, including CAOT, to identify gaps in practices and set cross-Canada standards. Each of the provinces/territories have been found to have differing practices; thus, cross-provincial standardization may lead to new knowledge and optimize advocacy efforts.

This presentation concluded with remarks on the current state of Canadian and international disability rights work. Canada is a signatory on the Convention on the Rights of Persons with Disabilities (United Nations, 2008). The Canadian Human Rights Commission is the national institution recognized by the United Nations for both the protection and promotion of human rights for Canadians. Working with the Commission, CASDA uses a mixed approach of diagnosis-specific, needs-based, and rights-based advocacy approaches to balance the limits and utility of diagnostic constructs with their practicality and usability for policy action.

[Consult the panelists' slides.](#)

Results

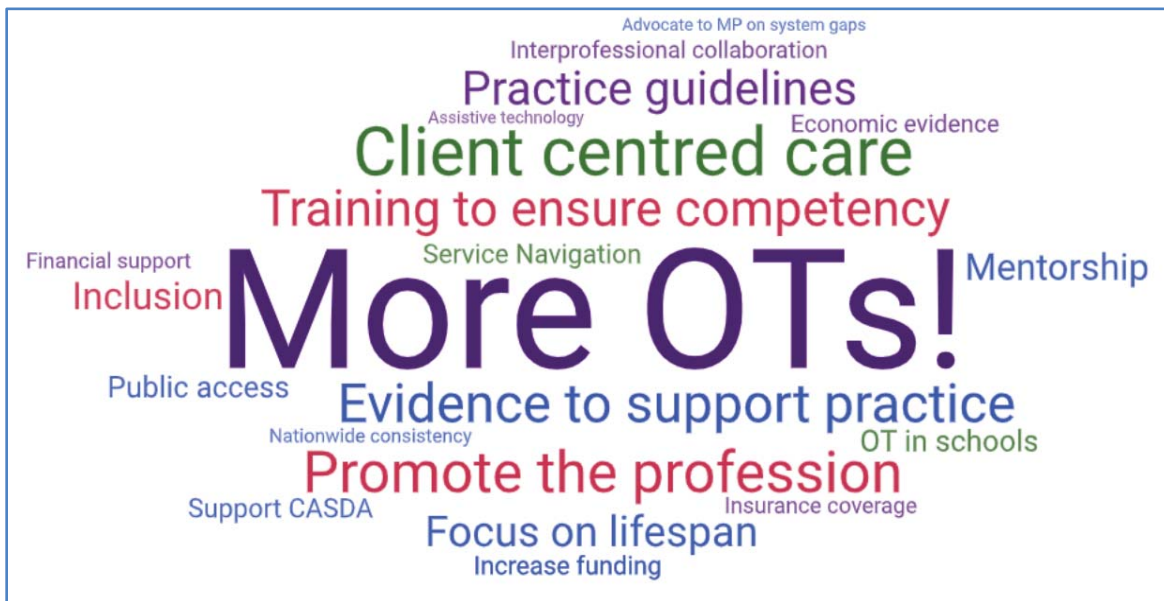
Participants were given the opportunity to share their opinions by means of an interactive phone application throughout the presentation, and they were welcome to add comments in the videoconference system chat box. See Appendix A for a complete list of the questions provided. The following section aims to synthesize participants' responses and ideas. This synthesis is a preliminary step to a more in-depth analysis of input received.

The word clouds below display the most common terms and ideas expressed by participants when asked to picture an ideal future scenario for occupational therapy services (Figure 1), and how that scenario can become a reality (Figure 2).

Figure 1. Word cloud of responses to: "In 5 years from today, what is the ideal scenario for occupational therapy services for *Autism-P* across Canada?"



Figure 2. Word cloud of responses to: "List 5 Concrete Actions that CAOT, in partnership with organizations like CASDA, can do to reach this ideal scenario?"



Reflecting on the unique contributions of occupational therapy for *Autism-P*, participants were asked what messages they would like for CAOT to share with the following four populations: fellow occupational therapists, *Autism-P*, other health professionals, and policy makers (see Question 13, Appendix A).

Participants expressed their wish for fellow occupational therapy colleagues to know that occupational therapy can be a helpful resource for *Autism-P* beyond childhood. Namely, occupational therapy can focus on needs and goals across the life course, including around employment and housing. Participants also broadly emphasized the importance of focusing on using occupation as treatment and on the strengths of each client using a strengths-based approach to practice. Additionally, participants highlighted the importance of considering the client's many environments, as well as occupational performance and engagement within these environments. Specifically regarding the social environment, occupational therapists are ideally positioned to help build capacity for people in supportive roles (e.g., family members, friends, employers). Last, the importance of evidence-based practice was considered a central message to communicate to fellow occupational therapists.

As for messaging to share with *Autism-P*, participant responses highlighted that the voices, needs, and goals of *Autism-P* are important to occupational therapists and guide all occupational therapy decision making. A second message was that occupational therapists help *Autism-P* by advocating for inclusion, independence, and self-determination in decision making during all life stages, such as regarding employment, housing, and facets of life beyond solely functional outcomes. Participants voiced that there is a lot of emphasis on treatment in early childhood, so many responses were focused on what occupational therapists can do beyond

the childhood years. Last, quality care driven by open communication and emphasis on person- and family-centered care is the philosophy of occupational therapy.

Next, when brainstorming what to share with other professional disciplines, the following key messages emerged from participant responses. Occupational therapists are not in competition with other disciplines. Responses also emphasized the value of collaborating in a strong interprofessional team, along with the desire for seamless communication in the process of providing quality care. Participants additionally responded that clarifying the occupational therapy role to members of other professions is important so that every team knows where an occupational therapist fits in within the assessment and treatment plan. For example, occupational therapists focus less on the specific diagnosis of autism and more on barriers and the goals of the person and family—less medically focused and more environmentally and contextually focused. Additionally, occupational therapy goes beyond simply providing pediatric care or helping to find employment opportunities, contributing to supporting all areas of daily living, at any stage of life.

Last, participants wanted policy makers to know the ways in which occupational therapy provides cost-effective interventions by improving clients' independence in society. Occupational therapy offers a unique perspective that needs to be better understood by policy makers and other professionals. Furthermore, there is a need for more inclusive practices and the potential creation of a coalition of organizations for *Autism-P*. Participants stressed the importance of clients and families sharing their stories to help increase policy makers' awareness about their needs and the unique contribution of occupational therapy to their lives.

Overall, the PIF engagement led to the proposal of strategies and recommendations for two-tier actions—for individual occupational therapists and for CAOT to advance a united national occupational therapy voice for *Autism-P*. Among the central themes that emerged is a need to develop a cross-Canada model of equitable, coordinated care and service access based on needs rather than diagnosis. Participants also stressed the need for occupational therapy to be funded throughout the lifespan to support *Autism-P*. Additionally, the creation of a robust occupational science practice network and guideline would help address the needs of *Autism-P* throughout the care continuum.

Next Steps

As a result of this stakeholder engagement, further discussions will be held between CAOT and CASDA regarding occupational therapy involvement in supporting *Autism-P*. A five-year strategic plan will also be mapped regarding the unique and complementary contribution of occupational therapy in serving *Autism-P* across the care continuum and throughout the lifespan. The strategic plan will recommend advocacy actions for individual practitioners and for CAOT, as well as propose key messages to disseminate to the following four distinct audiences: occupational therapists, *Autism-P*, other professional disciplines, and policy makers. These recommendations and advocacy actions will include initiatives relevant to the current Canadian context.

Conclusions

In addition to applying evidence-informed interventions, it has become vital to turn our attention to helping *Autism-P* navigate health, social, education, and employment service access and engagement in a meaningful life. Occupational therapists are well positioned to screen for autism, inform diagnosis with formal training, provide occupation-based assessment and intervention, support coordinated care, assist with systems navigation, and advocate for meaningful occupation for *Autism-P*, throughout both the care continuum and the life course.

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Appendix A. Mentimeter Questions

1. What is your current role?
2. Do you have lived experience with autism as a family member or close relative of a person with autism, or as a person with autism?
3. What primary province/territory do you work in?
4. What primary age group do you work with?
5. What primary setting do you practice in?
6. What type of funding source(s) cover occupational therapy services in this setting?
7. How many years of occupational therapy experience working with people with autism spectrum disorder do you have (less time on leave)?
8. Please share additional funding resources in your province/territory.
9. In 5 years from today, what is the ideal scenario for occupational therapy services across Canada?
10. Please list 5 practice resources that are needed to actualize this ideal scenario.
11. List 5 Concrete Actions that CAOT, in partnership with organizations like CASDA, can do to reach this ideal scenario?
12. List 1 or 2 concrete actions that you, as an occupational therapist, can do to reach this scenario?
13. When reflecting on the unique contribution of OT for people with autism...
 - a. What key message do you want to share with fellow OTs?
 - b. What key message do you want to share with people with autism & families?
 - c. What key message do you want to share with other professionals?
 - d. What key message do you want to share with policy makers?
14. Please rank the educational tool(s) we can use to best help...
 - a. Fellow OTs demonstrate their unique contribution for people with autism:
 - b. People with autism & families understand OTs unique contribution
 - c. Other professionals appreciate the unique contribution of OT for people with autism
 - d. Policy makers make decisions based on the unique contributions OTs can make.