Needs Assessment Snapshot: Perspective of Frontline Staff and Management on the Effects of COVID-19 and Physical Distancing Measures on People with Developmental Disabilities

What we did and what we asked:

An on-line survey was sent to Developmental Agencies in Ontario with the request that it be forwarded to staff. The survey was open from April 5 – 22, 2020 and asked about the effects of COVID-19 and physical distancing requirements on people with developmental disabilities, family members and staff working in the sector. Two hundred and fifty-four (254) people working in developmental services responded, 91% of whom were from Toronto and the surrounding area. While the results do not necessarily reflect the views of non-residential service providers across the province, they do provide important insights into the effects of the COVID-19 pandemic on people with developmental disabilities.

What We Found

- 92% of respondents reported that physical distancing requirements have caused major disruptions to the routines of people with developmental disabilities
- 64% reported people with developmental disabilities are unable to access all their usual supports
- 53% reported people with developmental disabilities have decreased access to health care
- 51% reported increased health and safety risks for people with developmental disabilities
- 33% reported people with developmental disabilities have lost employment

Respondents also provided qualitative descriptions of issues that further exacerbated the situation. Common issues identified for people with developmental disabilities were:
- Difficulty understanding the need for physical distancing and trouble adhering to guidelines
- No, or insufficient, access to technology to enable on-line socializing and supports
- Difficulty accessing testing and hospital care, if required, for those showing signs of COVID-19 because they were unable to have familiar support staff accompany them

Impacts on Health and Well-Being

A variety of impacts on the health and well-being of people with developmental disabilities were reported by respondents:
- 72% indicated increased social isolation
- 70% indicated an increase in challenging behaviours
- 70% indicated increased anxiety and depression

Respondents also described the following common issues related to health and well-being:

- Other negative emotions such as fear, confusion, stress and boredom
- Decreased independence and regression in skills
- Increased social vulnerability in the form of food and financial insecurity, and unstable housing/shelter access for some living with family or independently

Pre-existing Factors

Respondents indicated that these effects were exacerbated by pre-existing factors already affecting the lives of people with developmental disabilities, such as:

- General social exclusion
- Lack of a natural support system (family, friends)
- Lack of access to technology
- Unemployment, underemployment, job insecurity, and poverty
- Marginalization and underfunding of the developmental services sector

What can be done to address the situation now?

Helpful Strategies

Respondents endorsed many strategies to address the needs of people with developmental disabilities during the pandemic. The more common of those were:

- Clear evidence-informed instruction for when and how to effectively support a person being quarantined (63%)
- Information regarding apps clients can use to access supports, entertainment or social engagement (61%)
- Other resources to support social connection (61%)
- Real time on-line supports (e.g., chat messaging) (59%)
- Easy read tools to help clients with physical distancing (59%)
- Remote access to adapted programming (58%)
- Real time on-line supports from social service providers who know the client (58%)
- Timely access to medical care (58%)
- A Helpline (57%)

These results, and other suggestions provided by the respondents, were used to create a set of recommendations to meet specific needs of people with developmental disabilities during the COVID-19 pandemic.

- Increase access to technology as a source of meaningful activity and to connect with families and/or friends
- Establish a Helpline for support to:
  - Address challenging behaviours
  - Manage negative emotions and mental health issues
  - Establish new routines and activities
  - Access telehealth services
  - Plan hospital appointments or emergency visits
  - Find resources to address general challenges people are facing
- Establish Crisis Supports that can operate safely in the context of a pandemic
- Tools, resources, policies, procedures, and protocols to:
  - Increase activities/establish new routines, reduce boredom
  - Manage increases in challenging behaviours
  - Explain and implement physical distancing for people with developmental disabilities
  - Facilitate effective health care for people with developmental disabilities
  - Allow family or support staff to safely accompany the person into hospital when needed
  - Accessible COVID-19 testing (e.g., mobile testing for group home residents, people with mobility issues)
  - Provide supports to people who cannot use, or don't have access to, on-line technology (e.g., finding creative ways to do safe home visits, face-to-face service)
- Funding and other Financial Resources
  - Flexibility of funding (e.g., expansion of eligible purchases under Passport funding)
- Additional income supports
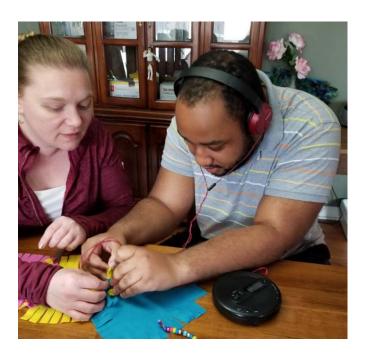
What long-term advocacy is required?

Based on the findings, several areas for long-term advocacy can be identified. These were not necessarily suggested by respondents but based on some of the challenges reported.
- Equity of access to health care (including but not limited to provision of necessary accommodations – even during a pandemic)
- Raise awareness in the general public and specific sectors, such as health care and law enforcement, of the specific challenges people with developmental disabilities experience during a pandemic and what accommodations and supports they may need
- Identify necessary services for which current remote/virtual models are not effective and develop safe face-to-face models for use during physical distancing

- Invest resources to close the technology gap for people with developmental disabilities
    - New/adapted technology to facilitate on-line access for people with developmental disabilities and training in its use
    - Free internet access and adequate data plans for people with developmental disabilities and their families during pandemics that enable them to access services and maintain social connections
    - Ongoing development of remote/virtual supports and special clinical services
- Inclusion of people with developmental disabilities in poverty reduction strategies
- Ensure the needs of people with developmental disabilities are accounted for in pandemic relief programs
- Support for ongoing needs assessment data collection to identify gaps in the system and inform pandemic/emergency planning (e.g., high-risk clients and families, assessment of supports, system capacity, triage protocols)

For the full report and other snapshots go to:
https://realxchange.communitylivingessex.org/human-resources-and-policies/

For more information contact the authors of the report:

Maria Huijbregts: MariaHU@familyservicetoronto.org
Barry Isaacs: barry.isaacs@surreyplace.ca
Janet Vogt: janet.vogt@surreyplace.ca

Sector Pandemic Planning Initiative (SPPI)