

**COVID-19: Toronto Developmental Services Alliance
Community Needs Assessment
Family Survey
Responses: April 18 – May 16, 2020**

**Preliminary Report
for the Research and Education Working Group
of the
Sector Pandemic Planning Initiative**

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Message to the Reader

This is a preliminary report from the Family Survey and focuses on the data from closed-ended questions (i.e., those which required respondents to select from multiple response options). The response options offered in these questions represent the anticipated effects of the physical distancing measures on the families of people with developmental disabilities. There were also open-ended questions on the survey but, due to the large volume of responses, the qualitative analysis of these questions is not yet finished.

The results presented in this preliminary report can provide a sense of the effects on families but they capture neither the unanticipated effects nor the detailed accounts that were reported by survey respondents in the open-ended questions. Once the qualitative analysis is finished, a revised (and complete) survey report will be issued.

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Executive Summary

- Data from 1,083 respondents was analyzed
 - Responses were received from across the province, although some regions are better represented than others
 - Collectively, respondents support 1,173 individuals with developmental disabilities, ranging in age from two to 77 years
 - Eighty-eight percent of respondents are parents of an individual with a developmental disability and nine percent are siblings
 - Most respondents (81 percent) live with the individual
 - Most respondents indicated that the person with a developmental disability requires access to multiple ongoing supports
- Loss of routine and impaired access to friends, family, and community were the most often cited effects on the person with a developmental disability
- Approximately half experienced increased behavioural issues and mental health issues
- Respondents indicated the need for resources and technology to enhance social connection and access to services for the person with a developmental disability
- Most respondents indicated an increased concern for the person with a developmental disability and were overwhelmed due to a lack of respite
- Respondents indicated the need for several supports and resources to help with the current situation, such as help with groceries, access to PPE, and access to counselling and/or group support for caregivers

Introduction

The Research and Education working group of the Sector Pandemic Planning Initiative (SPPI) undertook a needs assessment survey of families in the developmental services sector. The survey was designed to explore the impact of the COVID-19 pandemic, and the associated physical distancing policies and practices, on people with developmental disabilities and their families, and to solicit suggestions about the resources and supports needed. **Appendix 1** provides the definitions for terms used in this document.

Methods

For a copy of the online survey, please refer to **Appendix 2**.

The survey was disseminated to member agencies of the Toronto Developmental Service Alliance Network and the Provincial Network and other organizations that connect directly with families. Recipients of the email invitation (i.e., executive leads) were requested to share the survey link with families receiving services from, or connected to, their agency or organization; either via email or by posting on their website or social media.

A phone survey was piloted wherein staff at the Pegasus Community Project contacted families who received services from them, and could not access the online survey, to support them in completing the survey. Nine families completed the survey using this method.

This report is based on analysis of 1,083 responses received between April 18 and May 16, 2020. Eight hundred seventy-two (872) of respondents live in the same home with the person with a developmental disability (in a small percentage of these cases, the person with a developmental disability has moved back to the family home during the pandemic). Two hundred eleven (211) of respondents do not live with the person with a developmental disability. The latter group includes people in group homes, those living independently with support, and other living situations.

One open-ended question (pertaining to whether the respondent had the appropriate technology to access online resources) was included in this report (see page 9). The qualitative analysis of the responses involved one person coding the content, which was then reviewed by two other members of the coding team to ensure consensus.

Results

Results from the survey questions are not reported in the same order as they appear on the survey (Appendix 2). Graphs in the following sections show the proportion of respondents who chose each response category. The summary is purely descriptive; no statistical comparisons between groups have been made. The number of people who answered each question is provided in brackets after each question.

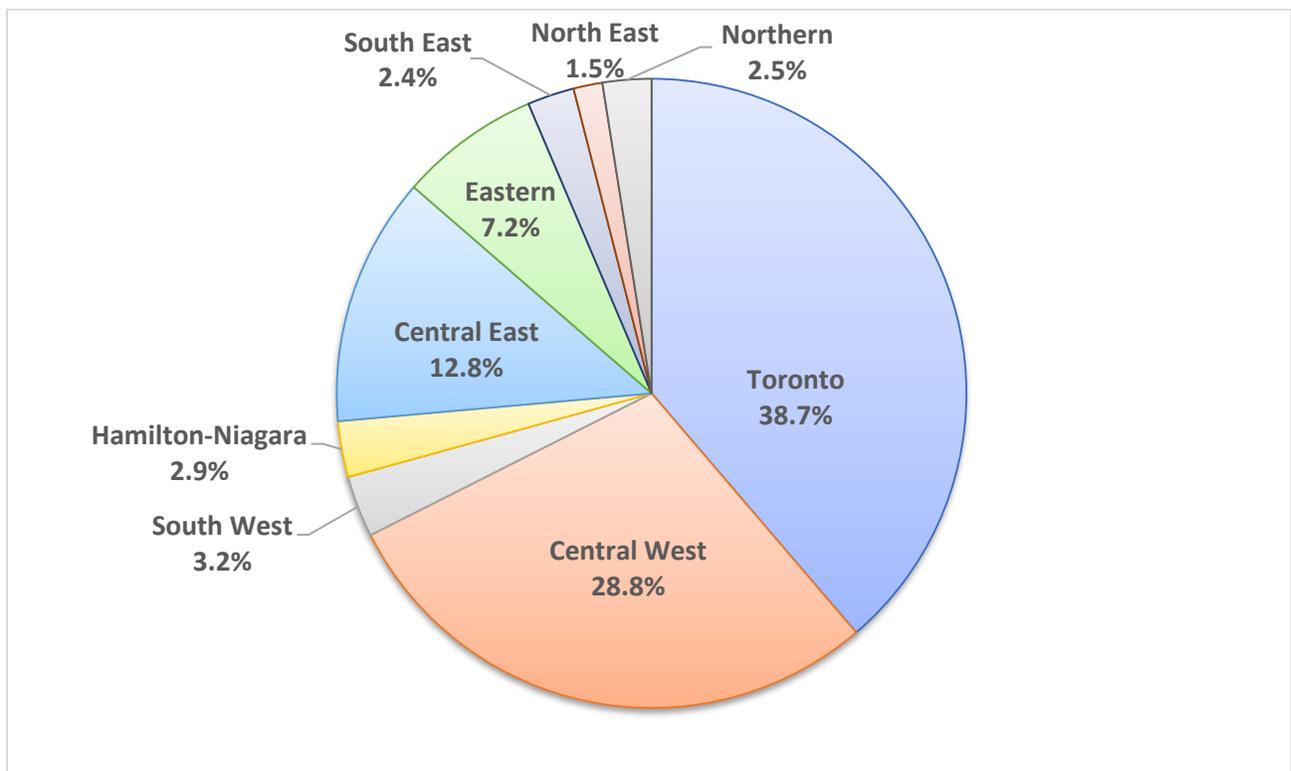
Who are the respondents?

Region

In what part of Ontario do you live? (N=1,079)

The provincial regions referenced in this report are those defined by Developmental Services Ontario. For these definitions, please refer to Appendix 1.

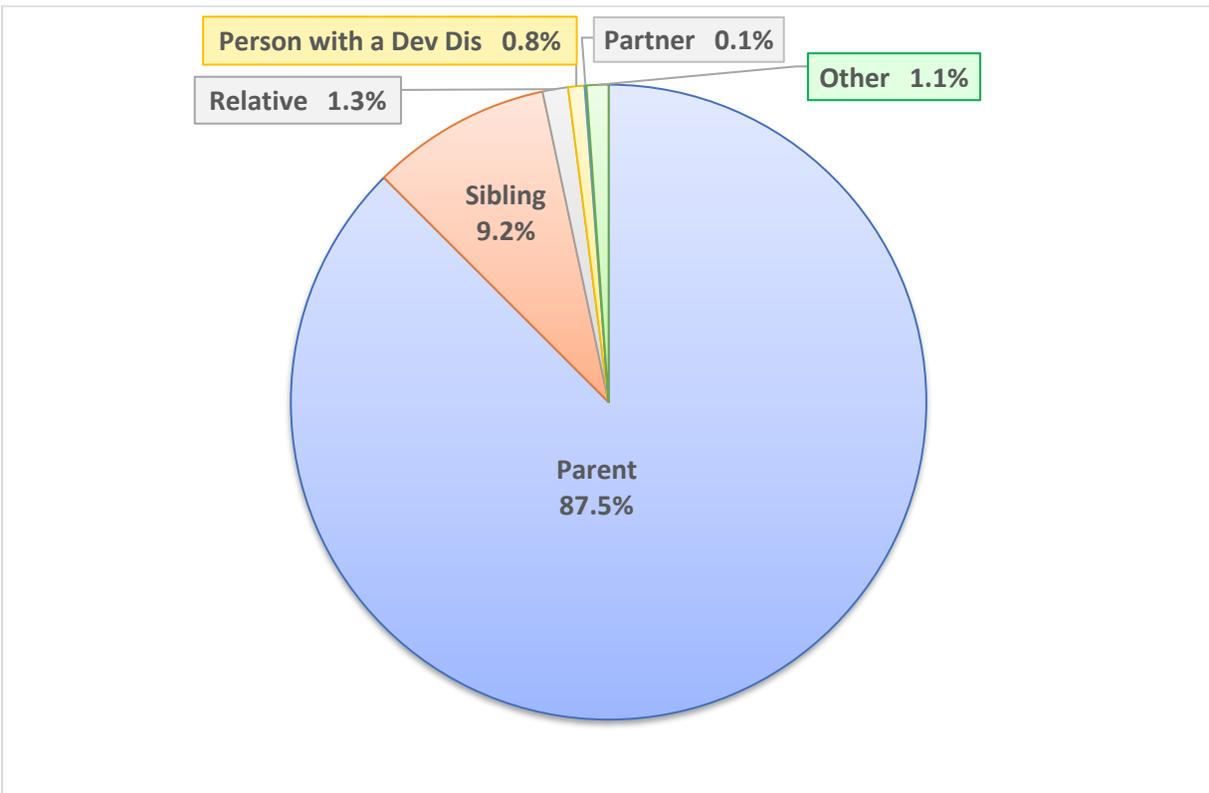
- Responses were received from all regions of the province, although some (e.g., Toronto) were over-represented and others (e.g., North East) under-represented
- The Toronto region had the highest representation (39 percent of the total)
- Central East and Central West combined accounted for 42% of responses



Relationship to the person with a developmental disability

What is your relationship to the person with a developmental disability? (N=1,080)

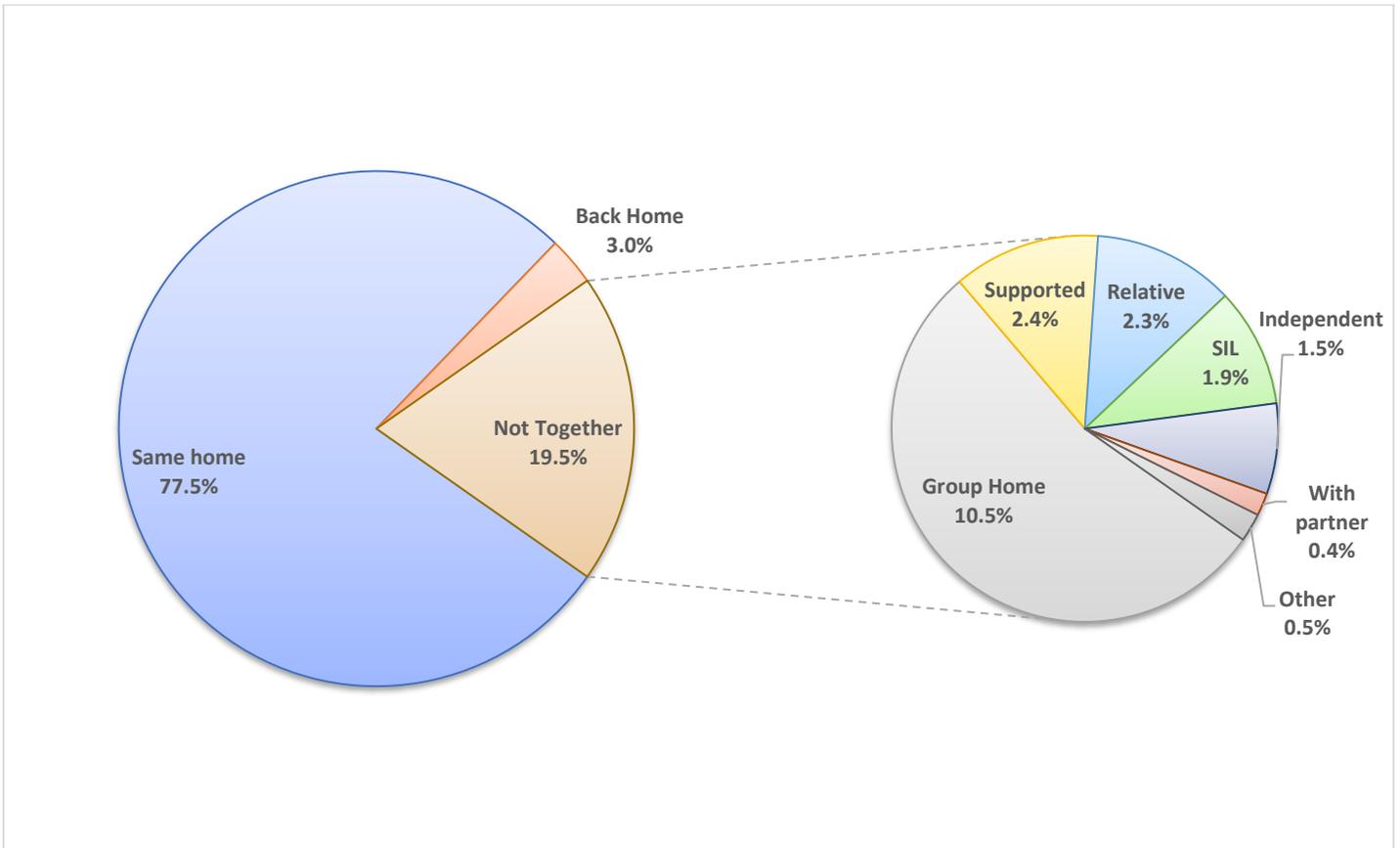
- Eighty-eight percent of respondents were parents
- Nine percent were siblings
- One percent were other relatives
- People with developmental disabilities, their partners, and others who support them accounted for two percent of the sample



Living situation

What are the living circumstances of the person (or persons) with a developmental disability? (N=1,083)

- Approximately 80 percent of respondents live in the same home as the individual(s)
 - Three percent (i.e., 33 individuals) have moved back in with family due to Covid-19
- Approximately 10 percent of the whole sample live in group homes, etc.
- Percentages for other living arrangements are also shown



How many people with a developmental disability do you support? (N=1,078)

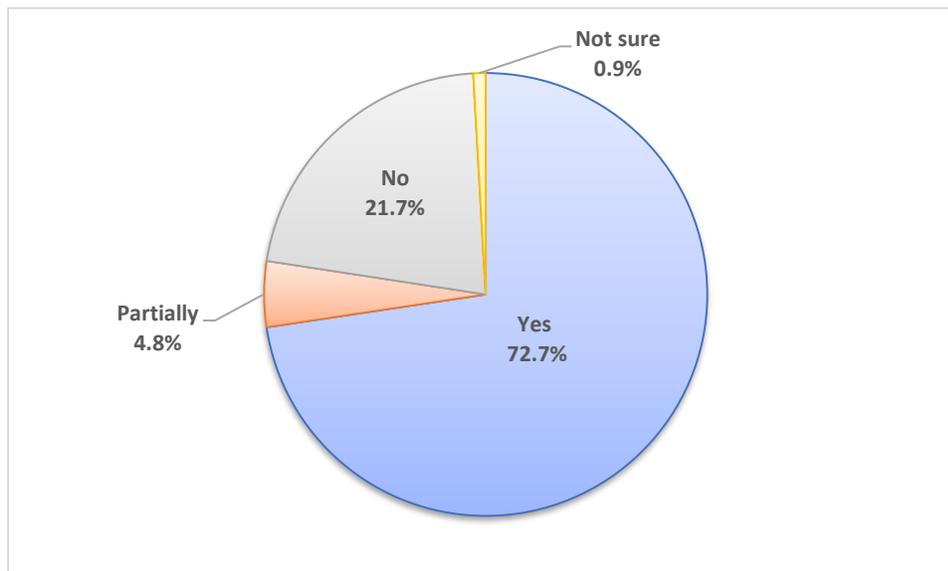
There was no survey question that asked this directly. The total number of people with developmental disabilities supported by each respondent was calculated based on their response to the question that asked the ages of the individuals they supported. People reported ages for one to four people. The breakdown is as follows:

People with DD supported by Respondent	Number of Respondents	Proportion of Sample
One	989	91.7%
Two	81	7.5%
Three	6	0.6%
Four	2	0.2%

Do you feel you have the appropriate technology (e.g., powerful enough computer, reliable internet access, webcam, etc.) to access real-time online supports? (N=941)

This question was open ended and responses were coded. As this was an online survey, the responses to this question will not necessarily be representative of all families. It excludes all of those without computer or internet access. It is highly likely they under-represent the proportion of families who **do not have** the necessary technology to access online supports. The 'partially' category includes those who had most or some of the appropriate technology or were in the process of obtaining it.

- Seventy-three percent of respondents have the appropriate technology
- Twenty-two percent do not
- Approximately 5 percent have some, but not all, the necessary hardware/software

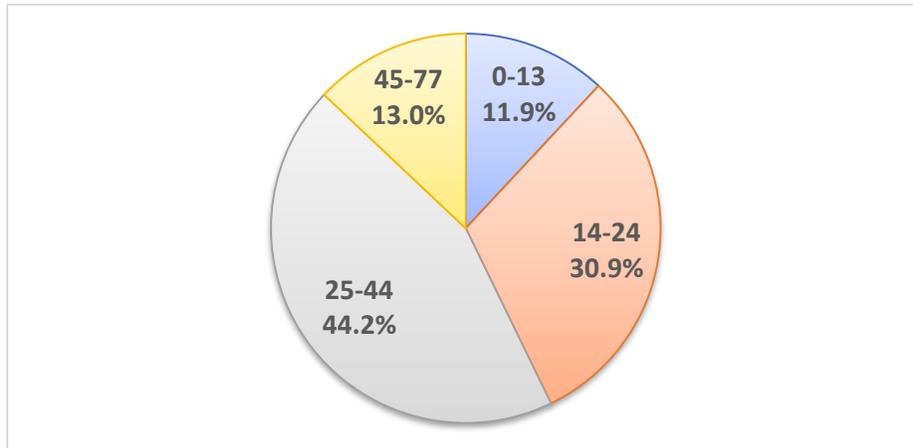


Who are the people with a developmental disability the respondents support?

Age

How old is the person (or persons) with developmental disability? (N=1,173)

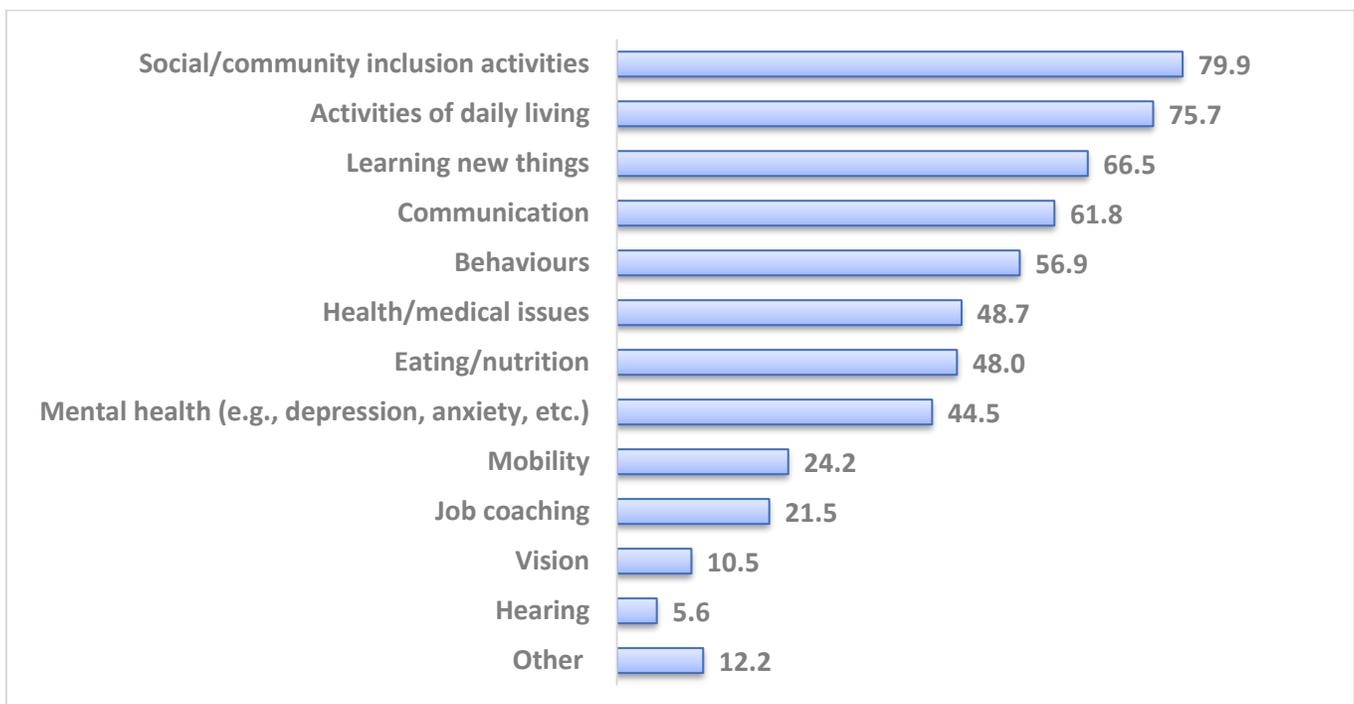
- Seventy-five percent of the people with developmental disabilities were between 14 and 44 years old
- The remaining 25 percent were equally split between those under 13 years old and those over 45



Their usual supports

For which of the following does the person with a developmental disability usually require supports or services? (N=1,083)

- Most respondents indicated that the person with a developmental disability had multiple needs
- The most frequently endorsed supports were those for social/community inclusion, activities of daily living (ADLs), skill building and learning, communication, and behaviours
- Approximately 50 percent of respondents reported access to supports for health and medical issues, eating and nutrition, and mental health



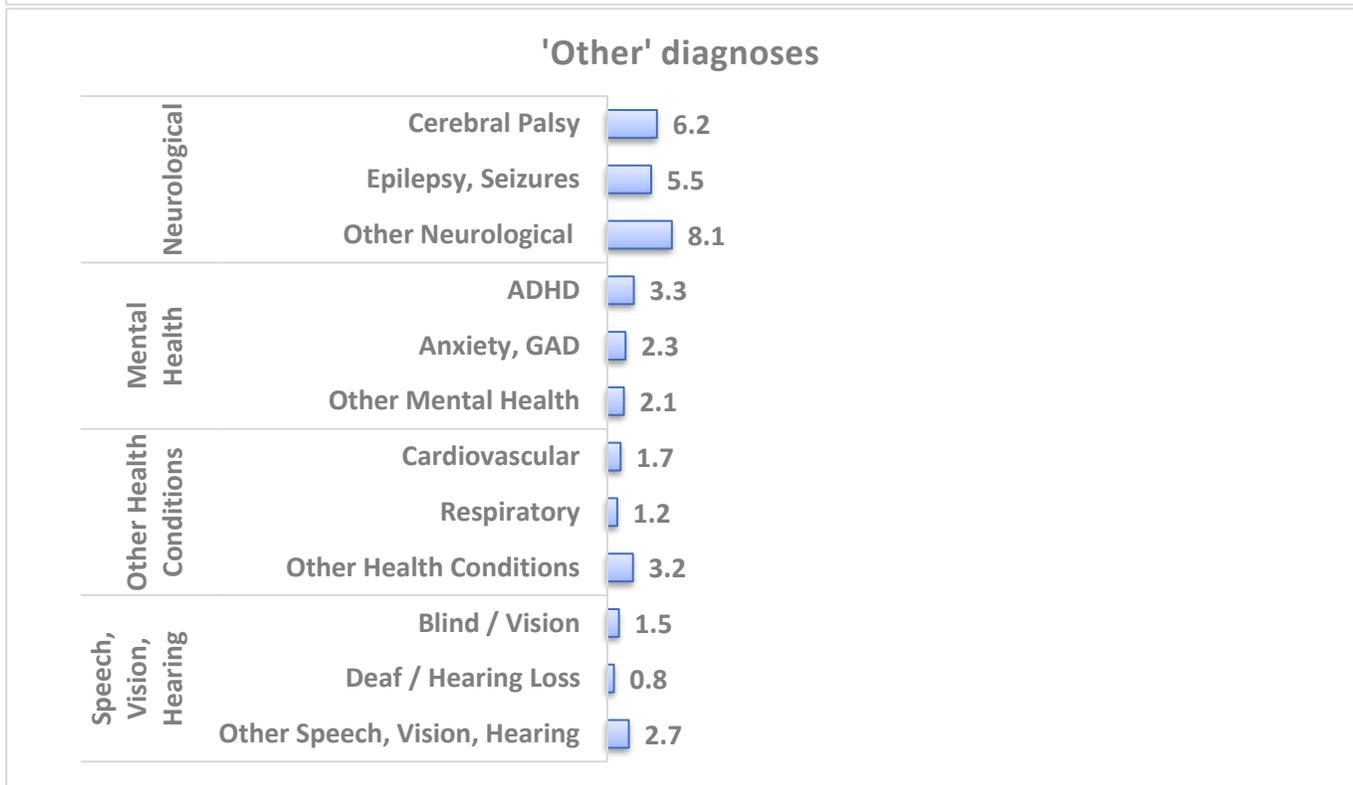
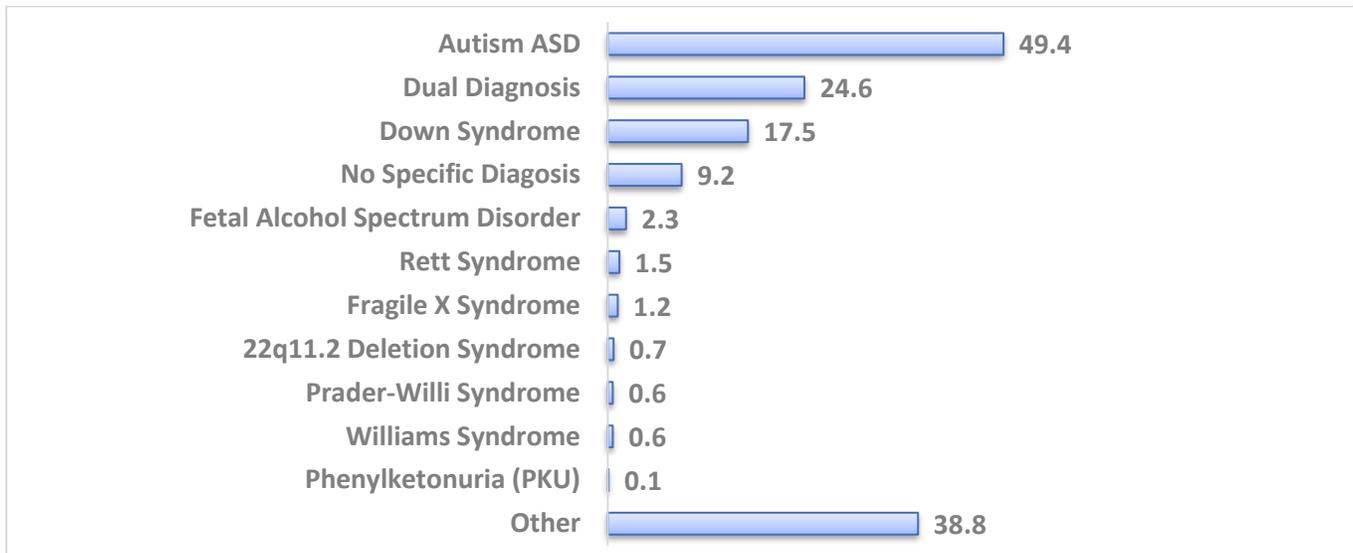
Diagnoses

If the person with a developmental disability has a diagnosis which you believe contributes to the impact of physical distancing and social isolation, please tick the applicable box(es).

(N=965)

Three hundred seventy-four respondents used the comment option to report diagnoses not listed as response options (see 'Other' in the first graph below). The most prevalent of these are presented in the second graph. The percentages for both graphs are calculated using the whole sample size (N=965) to facilitate comparison.

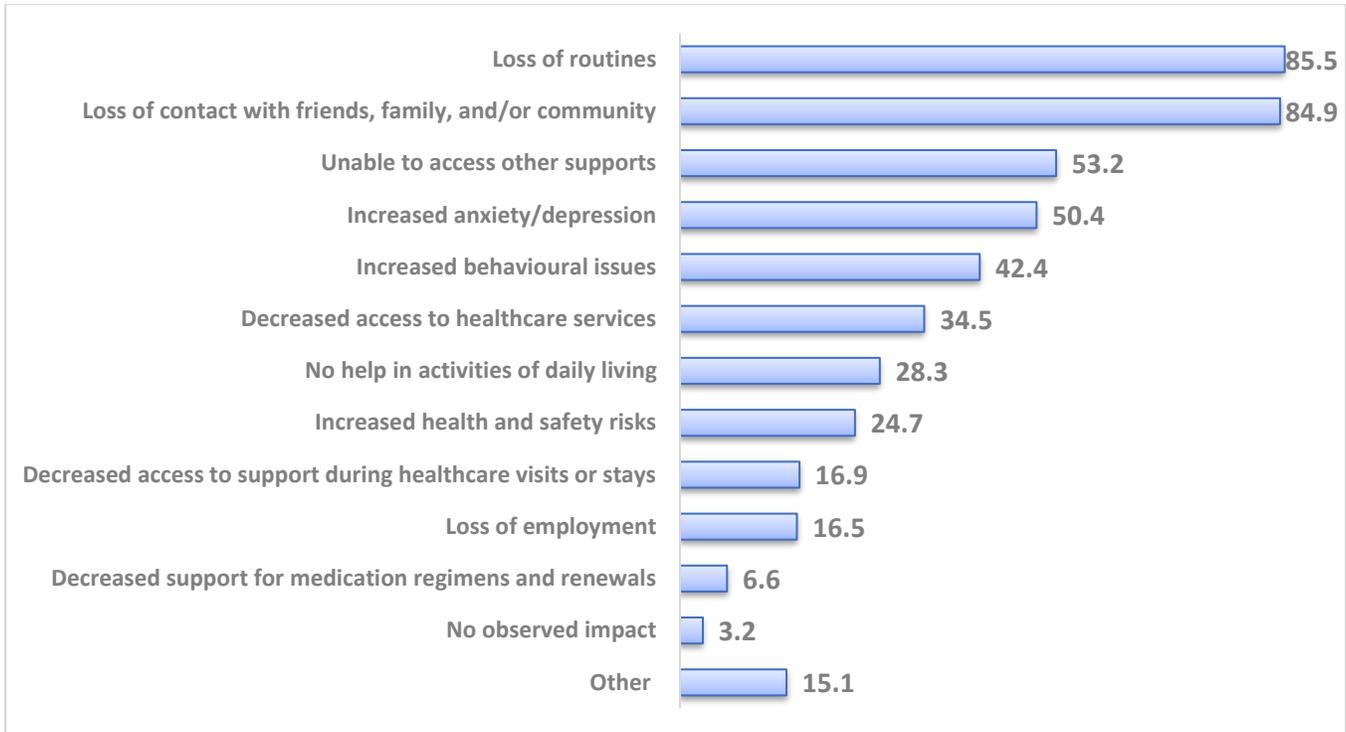
- The most prevalent diagnoses were autism (or ASD), dual diagnosis, and Down syndrome



Effects on the person with a developmental disability and the supports needed

What effects of physical distancing have you noticed on the person (or persons) with a developmental disability? (N=1,083)

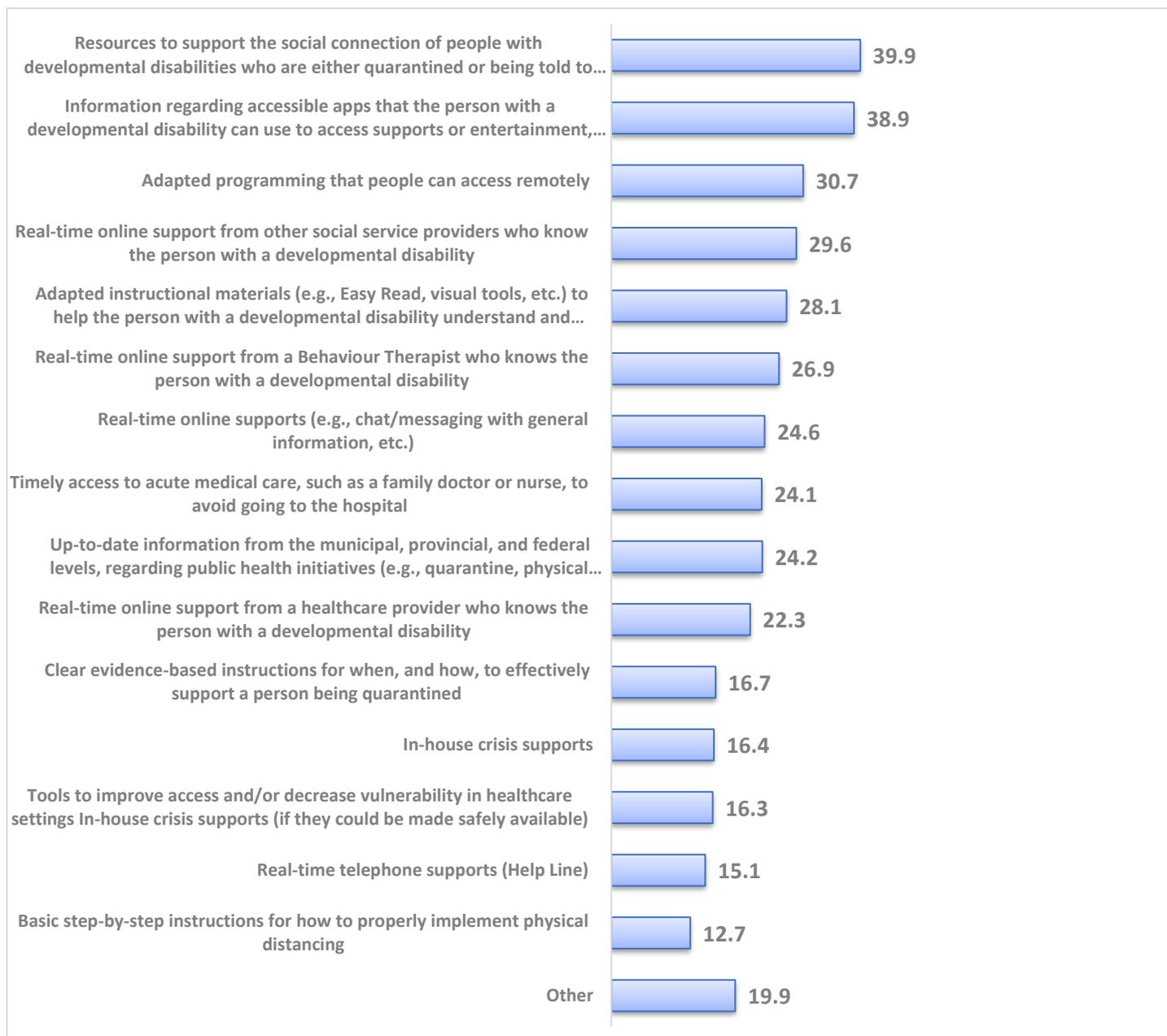
- Over 80 percent of respondents endorsed loss of routines and loss of connection with friends, family, and community
- Approximately half of respondents reported increased anxiety, depression, and behavioural issues
- Over half indicated they were unable to access supports
- A broad range of other issues were reported including issues with safety and healthcare



Which of the following kinds of supports and resources would help you meet the current needs of the person with a developmental disability (i.e., during this pandemic and physical distancing)? (N=1,083)

Although the level of endorsement for these items may appear relatively low, the responses provided in the ‘other’ category, currently being analyzed, are better able to capture the effects not covered in the response options provided and will yield additional information.

- Support to enhance social contact was the most endorsed item
- Many respondents endorsed items describing access to technology that would either increase social contact or enable the receipt of supports services, including apps, remote or on-line access too professionals and programs
- Information and resources in several areas was identified as a need by some, such as instructions for quarantine, tools to improve healthcare access

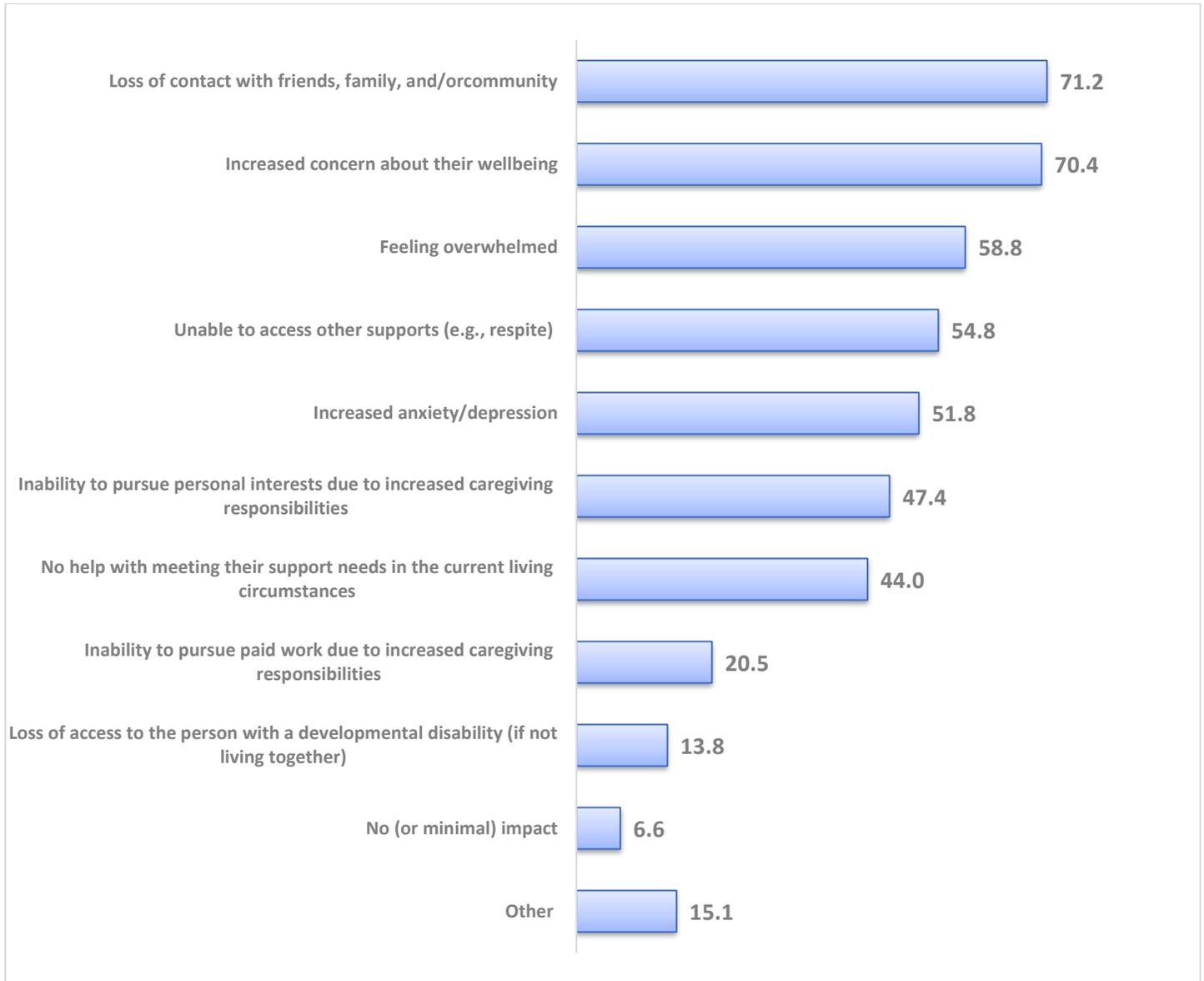


* Axis labels truncated; refer to survey in Appendix 2 for the full category labels.

Effects on caregivers, supports needed, and resources they have at hand

How has physical distancing, and its effect on the person you support, affected your day-to-day life? (N=1,083)

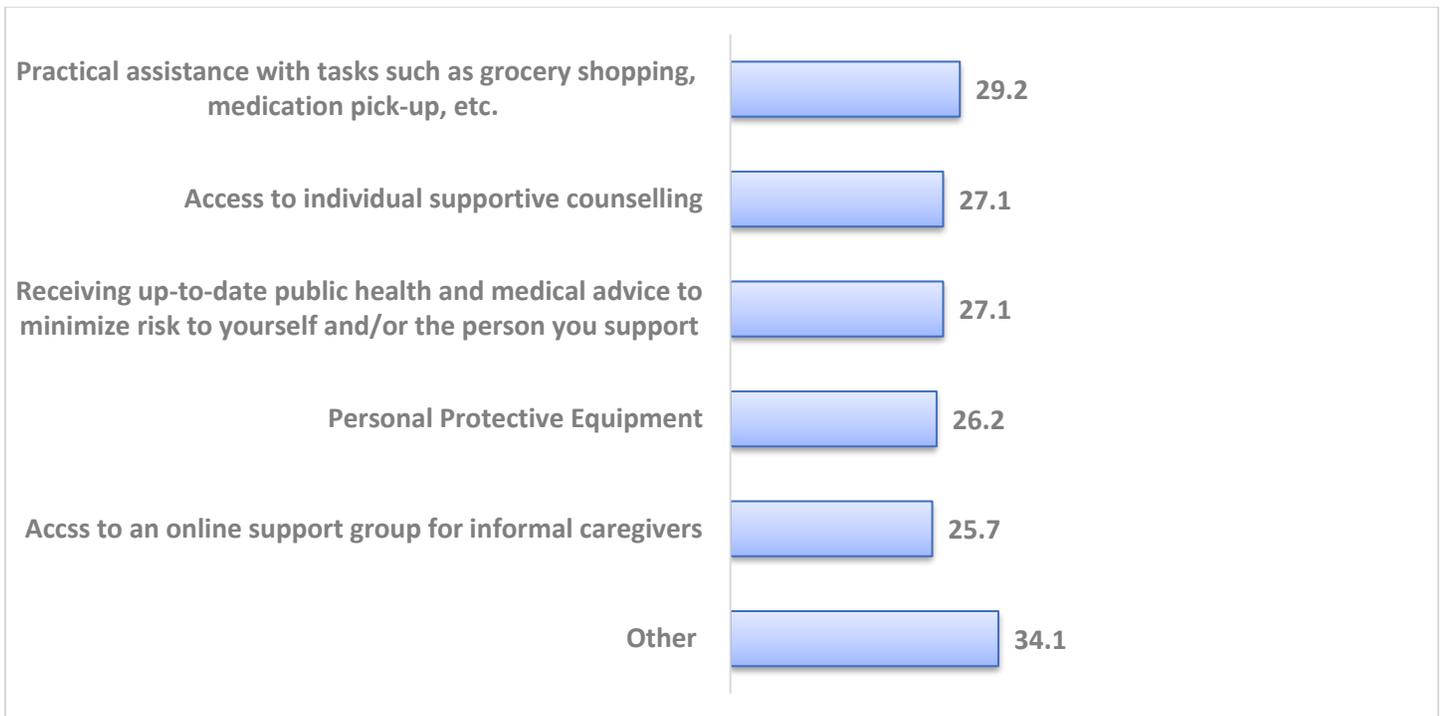
- Over 70% of respondents indicated they were experiencing loss of contact with family and friends as well as an increased concern for their family members with developmental disability
- Over half reported feeling overwhelmed and that they were unable to access supports such as respite
- A variety of other impacts were reported



What supports and resources would help you maintain your own health, safety and well-being while supporting the person with a developmental disability during the current situation? (N=1,083)

Respondents tended to endorse fewer options provided in the quantitative questions related to their own needs, as opposed to the questions asking about the needs of the person with a developmental disability. The responses provided in the ‘other’ category, currently being analyzed, are better able to capture the effects not covered in the response options provided. The qualitative analysis will provide additional information about family needs.

- No one particular type of support listed as an option in this question stood out as being more helpful than any other
- Between 25 and 30% of respondents endorsed each item



Discussion and Limitations

The large number of responses, and the rapidity with which they came in (over a four-week period), is an indication of the urgent need families are experiencing due to the pandemic. It is important to remember that many people with developmental disabilities rely on regular and frequent services and supports, across the lifespan, to enable them to function in daily life and participate fully in their community. Some common examples of these supports include various forms of therapy; support workers to help with activities of daily living, community participation, and social functioning; and oftentimes specialized clinical and healthcare supports. We may conclude from the results of this survey that the disruptions to their usual supports and services has negatively impacted the experiences of people with developmental disabilities as well as their caregivers. These impacts are felt by both the person with a developmental disability and the caregiver, regardless of whether they live together or not.

Respondents most often indicated that supports to facilitate social contact for people with developmental disabilities are needed. Respondents also endorsed items relating to online supports for people with developmental disabilities as potentially helpful for some, but not all people with developmental disabilities. About 30 percent indicated the need for some form of practical support to help them balance the work of caregiving and completing day-to-day tasks. About a quarter of the respondents also indicated individual counselling or an online support group would be helpful to them. It is important to note, however, that over 20 percent of respondents indicated they do not have the appropriate technology to access real-time online supports. In addition, people who have no computer or online access were unable to respond at all to this survey (with the exception of the nine families included in the phone survey pilot). Therefore, while online supports may help a large number of people, there is likely a significant minority of people who cannot use them.

Finally, as noted at the beginning of this report, these results do not represent a complete analysis of the survey responses. The qualitative analysis of the open-ended questions will yield a more informed understanding of the experiences of families during the pandemic. The results of both the quantitative and qualitative analyses will be integrated into a final report.

Appendix 1. Definitions

Provincial Regions:

- Toronto Region (Etobicoke, North York, Scarborough)
- Central East Region (Durham, Kawartha Lakes, Simcoe, York, Peterborough)
- Central West Region (Dufferin, Halton, Peel, Waterloo)
- Eastern Region (Ottawa Region, Renfrew, Stormont)
- Hamilton-Niagara Region (Brant, Haldimand-Norfolk)
- North East Region (Cochrane, Muskoka, Nippissing, Parry Sound)
- Northern Region (Algoma, Kenora, Sudbury, Thunder Bay)
- South East Region (Frontenac, Hastings, Lanark)
- South West Region (Bruce, Chatham-Kent, Essex)

Appendix 2. Online survey

The Toronto Developmental Services Alliance would like to hear from the families and caregivers of people with developmental disabilities about the challenges they're facing due to the COVID-19 pandemic. Developmental service agencies around the province are busy trying to collect resources and find new ways to support people. The purpose of this survey is to help inform this work.

The results of this survey will be summarized and shared with developmental service agencies in Ontario. It may also be published at a future date. We take your privacy seriously. The information collected in this survey will be kept confidential.

Even if you disclose your name when responding, we will not share your name, or other confidential information, with anyone.

We encourage you to consider input from the person with a developmental disability you support when answering the questions that apply to the impact on them (i.e., questions 10, 11, 15).

1. By completing this survey, I agree to the use of the information I provide for the purpose stated above.
 - Yes
 - No

2. In what part of Ontario do you live?
 - Toronto Region (Toronto, East York, Etobicoke, North York, Scarborough)
 - Central East Region (Durham, Kawartha Lakes, Simcoe, York, Peterborough)
 - Central West Region (Dufferin, Halton, Peel, Waterloo)
 - Eastern Region (Ottawa Region, Renfrew, Stormont)
 - Hamilton-Niagara Region (Brant, Haldimand-Norfolk)
 - North East Region (Cochrane, Muskoka, Nipissing, Parry Sound)
 - Northern Region (Algoma, Kenora, Sudbury, Thunder Bay)
 - South East Region (Frontenac, Hastings, Lanark)
 - South West Region (Bruce, Chatham-Kent, Essex)
 - If you're unsure, please provide your postal code in the comment box.

3. Which of the following applies to you? Tick off all that apply.
 - I am a **parent** of a person with a developmental disability
 - I am a **sibling** of a person with a developmental disability
 - I am a **partner** of a person with a developmental disability
 - I am a **relative, but not an immediate family member**, of a person with a developmental disability
 - Other (i.e., I support a person with a developmental disability but am neither a relative nor a paid caregiver of that person)

4. How old is the person (or persons) with a developmental disability?
 - Person 1 (Please specify)
 - Person 2 (Please specify)
 - Person 3 (Please specify)

5. What are the living circumstances of the person (or persons) with a developmental disability? Tick off all that apply.
 - At home with me

Appendix 2. Online survey

- In another family member's home
 - Independently with a partner
 - In a group home
 - In supported independent living (SIL)
 - Independently on their own
 - Supported living arrangements (other than SILs)
 - Other (please specify)
6. If the person with a developmental disability has a diagnosis which you believe contributes to the impact of physical distancing and social isolation, please tick the applicable box(es).
- Autism
 - Down Syndrome
 - Rett Syndrome
 - Prader Willi
 - Williams Syndrome
 - 22q11 Deletion
 - Fragile X
 - Smith Lemli Optiz
 - PKU
 - FASD
 - Dual Diagnosis (i.e., additional mental health disorder)
 - No specific diagnosis
 - Other diagnosis (please specify)
7. For which of the following does the person with a developmental disability usually require supports or services?
- Vision
 - Hearing
 - Mobility
 - Health/medical issues
 - Eating/Nutrition
 - Mental health (e.g., depression, anxiety, etc.)
 - Behaviours
 - Learning new things
 - Communication
 - Activities of daily living
 - Job coaching
 - Social/community inclusion activities
 - Other (please specify)
8. What effects of physical distancing have you noticed on the **person (or persons) with a developmental disability**? Tick off all that apply.
- Loss of contact with friends, family, and/or community
 - No help in activities of daily living
 - Unable to access other supports
 - Increased anxiety/depression
 - Increased behavioural issues
 - Increased health and safety risks
 - Loss of routines

Appendix 2. Online survey

- Loss of employment
- Decreased access to healthcare services
- Decreased access to support during healthcare visits or stays
- Decreased support for medication regimens and renewals
- No observed impact
- Other (please specify)

9. Please use this space to describe examples of these effect(s) on **the person with a developmental disability**.

10. How has physical distancing, and its effect on the person you support, affected **your** day-to-day life? Tick off all that apply.

- Loss of contact with friends, family, and/or community
- No help with meeting their support needs in the current living circumstances
- Unable to access other supports (e.g., respite)
- Increased anxiety/depression
- Increased concern about their wellbeing
- Inability to pursue paid work due to increased caregiving responsibilities
- Inability to pursue personal interests due to increased caregiving responsibilities
- Feeling overwhelmed
- Loss of access to the person with a developmental disability (if not living together)
- No (or minimal) impact
- Other (please specify)

11. Please use this space to describe examples of the impact on **you**, as someone who supports a person with a developmental disability.

12. What supports and resources would help you maintain **your own health, safety and wellbeing** while supporting the person with a developmental disability during the current situation? Tick off all that apply.

- Access to an **online support group** for informal caregivers
- Access to **individual** supportive counselling
- Personal Protective Equipment
- Receiving up-to-date public health and medical advice to minimize risk to yourself and/or the person you support
- Practical assistance with tasks such as grocery shopping, medication pick-up, etc.
- Other (please specify)

13. Which of the following kinds of supports and resources would help you meet the **current needs of the person with a developmental disability** (i.e., during this pandemic and physical distancing)? Tick off all that apply.

- Real-time **telephone** supports (Help Line)
- Real-time **on-line** supports (e.g., chat/messaging with general information, etc.)
- Real-time **on-line** support from a Behaviour Therapist who knows the person with a developmental disability
- Real-time **on-line** support from other social service providers who know the person with a developmental disability
- Real-time **on-line** support from a healthcare provider who knows the person with a developmental disability
- Timely access to acute medical care, such as a family doctor or nurse, to avoid going to the hospital

Appendix 2. Online survey

- Resources to support the social connection of people with developmental disabilities who are either quarantined or being told to implement physical distancing
- Up-to-date information from the municipal, provincial, and federal levels, regarding public health initiatives (e.g., quarantine, physical distancing, testing, etc.)
- Basic step-by-step instructions for how to properly implement **physical distancing**
- Clear evidence based-instructions for when, and how, to effectively support a person being **quarantined**
- Adapted instructional materials (e.g., Easy Read, visual tools, etc.) to help the person with a developmental disability understand and follow physical distancing and quarantine directives
- Adapted programming that people can access remotely
- Information regarding accessible apps that the person with a developmental disability can use to access supports or entertainment, or help meet their social needs
- Tools to improve access and/or decrease vulnerability in healthcare settings
- In-house crisis supports (if they could be made safely available)
- Other (please specify)

14. Can you describe a situation where you **would have benefited** from support but were **unable to access** it due to the physical distancing restrictions?

15. Do you feel you have the appropriate technology (e.g., powerful enough computer, reliable internet access, webcam, etc.) to access real-time online supports?

16. Do you have the necessary resources (e.g., personal computer, printer, scanner) to submit for Passport or Special Services at Home reimbursements, if relevant?

17. In your opinion, what are the most pressing needs for advocacy during this time?

18. What resources have you found particularly helpful during the current situation (i.e., COVID-19)? Please provide the details below.

19. Is there anything you want to add that we have not included in this survey? Please provide details.