COVID-19: Toronto Developmental Services Alliance Community Needs Assessment Survey

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

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Table of Contents

Executive Summary

- This report provides <u>preliminary results</u> of a survey exploring the impact of policies and practices as a result of the COVID-19 pandemic on Developmental Services staff, people with developmental disabilities, and those who support them.

- Two hundred twenty-five responses were received from 19 organizations (7 outside Toronto).

- **There are a variety of effects on people with developmental disabilities reported** across both residential and non-residential settings, which included: disruption of routines, loss of the usual services, supports, and programming, and social isolation, resulting in an increase in anxiety and challenging behaviours.

- **Effects on informal caregivers included:** increased responsibilities (i.e., 24/7 childcare), lack of supports, an inability to meet their own needs (e.g., paid work, respite), resulting in increased stress, anxiety, and depression. In addition, parents whose children live in other settings are now separated from them.

- **Staff are experiencing** a high level of stress and anxiety and increased concern for the wellbeing of clients, families, themselves, and their own families
  - A large proportion of residential staff expressed concern about their own safety due to inadequate Personal Protective Equipment (PPE)
  - Staff from non-residential organizations expressed frustration in trying to adequately meet clients' needs while working remotely

- **Staff indicated they would benefit from** timely communication of reliable information (e.g., public health directives) and reassurance from management
  - Almost all staff from residential providers indicated the need for supports to maintain their health and wellbeing, both physical and mental (e.g., PPE, Employee Assistance Program (EAP))
  - Many staff from non-residential organizations indicated the need for updated protocols for on-line privacy to support remote service

Executive Summary

- There was a high degree of endorsement for all the options provided in the question about **supports and resources for clients**

    o Respondents from residential providers most often indicated the need for resources related to health issues including: Timely access to acute medical care to avoid hospital visits, clear evidence-based instructions for how (and when) to effectively support a person being quarantined, and up-to-date information regarding public health initiatives

    o Respondents from non-residential providers most often indicated the need for access to on-line supports and programming

- Despite some limitations, we believe that this survey provides a good snapshot of the many challenges faced by clients with developmental disabilities and their formal and informal caregivers during this initial phase of the COVID-19 pandemic

- The results of this survey will guide further advocacy efforts on behalf of the sector, in addition to the development of further tools and resources

Introduction and Methods

Introduction:

The Research and Education working group of the Sector Pandemic Planning Initiative (SPPI) was asked to do a needs assessment survey of developmental service agency staff involved in client care, their managers, and senior level directors. The survey was designed to explore the impact of policies and practices as a result of the COVID-19 pandemic on staff, people with developmental disabilities, and those who support them and to solicit suggestions about the resources and supports needed. **Appendix 1** provides the definitions for terms used in this document.

Methods:

An on-line survey was developed, with input from the working group, and was tested with five early respondents to ensure that questions were clear and the survey platform (Survey Monkey) was working properly. For a copy of the whole survey, please refer to **Appendix 2**.

The survey was disseminated to member agencies of the Toronto Service Providers Network and the Provincial Network. Recipients of the email invitation (i.e., executive leads) were encouraged to share the survey link with their direct support workers and management.

The sample used for analysis of the quantitative data (i.e., categorical questions) is comprised of 220 respondents (91 from residential settings and 129 from non-residential settings). Five respondents were omitted from the quantitative analysis because they did not disclose the organization they worked for. Consequently, there was no way to categorize their responses as representing either agencies that <u>do provide residential services</u> or those that <u>do not provide residential services</u>.

A qualitative content analysis was performed on the open-ended questions (e.g., 9, 11, 15-18) and the comments fields from specific categorical questions (e.g., 8, 10, 12-14). Each question was analyzed and coded individually by two or three members of the team; emerging themes were identified; and consensus was reached. Themes emerging from the various questions were synthesized into a summative analysis. Table 4A (**Appendix 4**) presents a detailed summary of the themes pertaining to impacts and contributing factors identified through the qualitative analysis. Table 4B presents the resources and supports suggested by survey respondents. The summaries of coding results for each question are presented in **Appendix 5**.

The following table presents the breakdown of responses by organization, region, and role within the organization. Agencies providing residential services are highlighted in red font.

Organization	Region	Executive	Director	Manager	Front-line	Other
A	Central East	1				
B	Hamilton-Niagara	1				
C	Toronto	1				
D	Toronto	1				
E	Central East	1				
E	Hamilton-Niagara		1			
E	Toronto	1				
F	Toronto	1				
G	North East	1				
H	Toronto	2				
H	Toronto		1			
H	Toronto					(Undisclosed) 1
I	Toronto		1			
Ji	Toronto				1	
Jii	Toronto (3)		1		2	
K	Toronto (14)			2	12	
L	Toronto	1				
M	Toronto	1				
N	Toronto	1				
O[1]	Central East (4)				3	(Supervisor) 1
O[1]	Toronto (67)			3	59	(See footnote 2) 5
P	Toronto (4)				4	
Q	Toronto	1				
R	Central East	1				
Jiii	Northern (3)				2	(Coordinator) 1
Jiii	Toronto (103)	2		13	85	(See footnote 3) 3
S	Toronto		1			
Undisclosed	Toronto				5	
Independent[4]	Toronto				1	
		17	5	18	174	11

1.) One respondent (from Toronto region) listed their organization(s) as *O & R*.
2.) Other: Supervisor (3 homes); finance clerk; admin assistant; residential counsel/Team leads; holistic therapists.
3.) Other: Project manager; Health Records clerk; School Support worker.
4.) Respondent wrote ***Health care service to individual with developmental disabilities***.

This preliminary report is based on analysis of 225 responses received by April 12, 2020. Seventy-six percent of responses were from direct client service providers, *but these represented only four agencies, all in Toronto.* There was limited representation from agencies outside of the Toronto region and these responses tended to be from leadership (Executive level or Directors). Twenty-nine additional responses have been received since April 12, 2020 and will be incorporated into the analysis for the final report.

Results

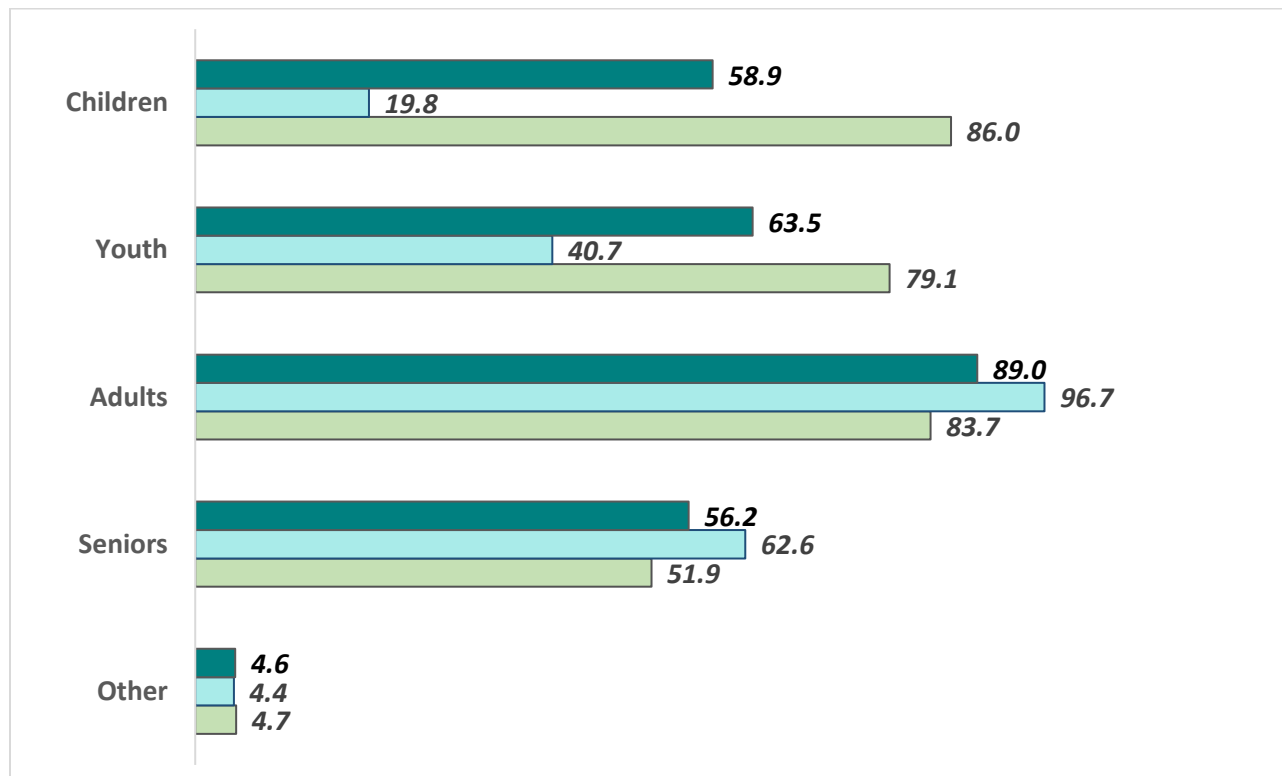Part One presents the quantitative results. Part two presents the qualitative analysis.

Part One: Quantitative Results

The graphs below represent the proportion of respondents who chose each response category. The summary is purely descriptive; no statistical comparisons between groups have been made. Questions 4 through 7 provide descriptive information about the respondents and the agencies they work for. The breakdown of responses to 'other' categories for these questions is provided in **Appendix 3**. Questions 8, 10, and 12 through 14 are concerned with the impacts of COVID – 19 on people with developmental disabilities, their family caregivers and/or support staff, and what resources and supports would help them.

	Overall Sample
	Residential agencies
	Non-residential agencies

4. **Who are the people your organization supports?** (N=220; residential = 91; non-residential = 129)
   - Almost 90% of **respondents** provide service to adult clients and just over half serve seniors.
   - Roughly 80% or more of **non-residential** service respondents provide services for children and youth
   - Of the staff from **residential providers** that responded, less than 20 percent provide services for children and roughly 40 percent provide services for youth
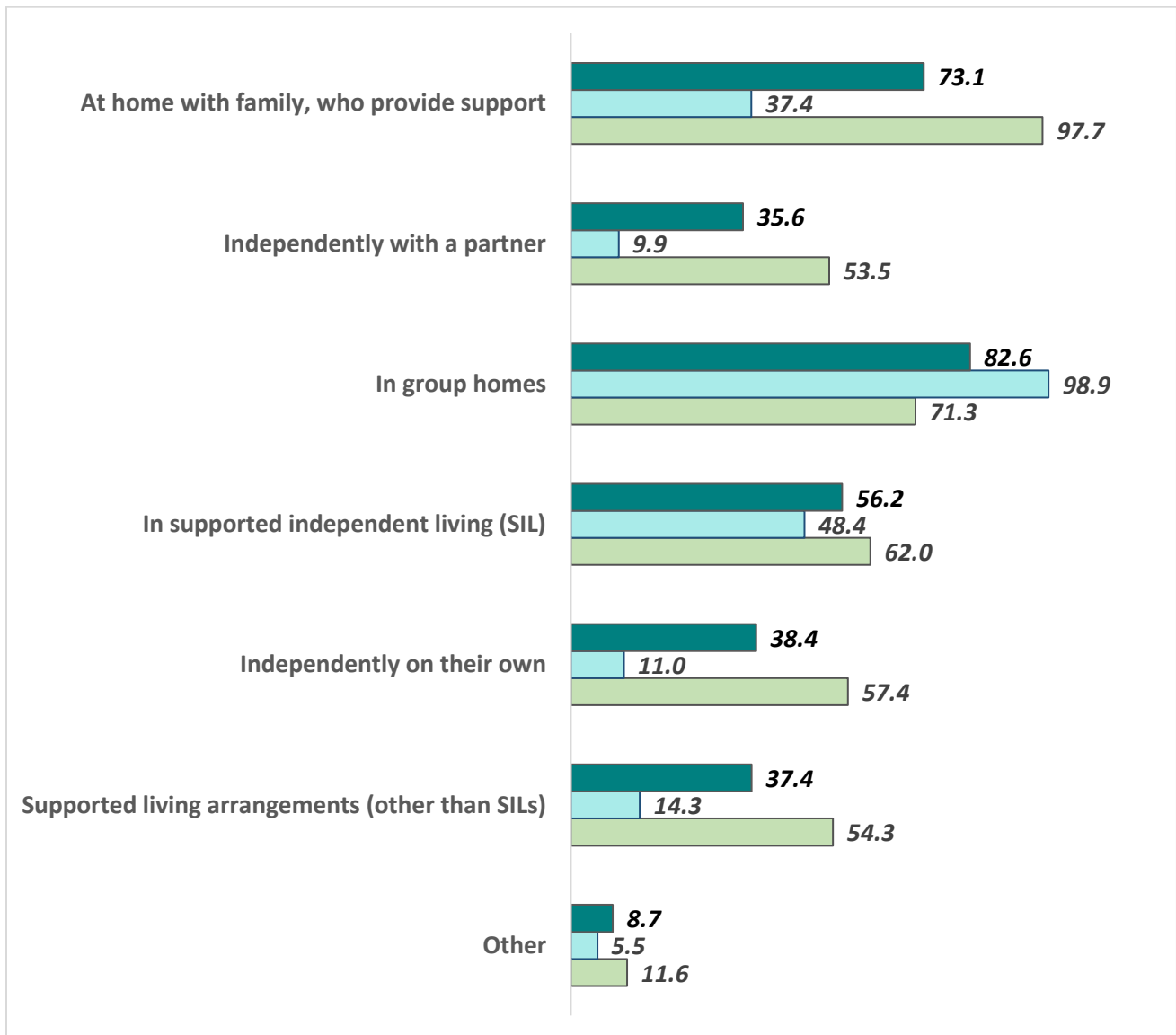
Results

5. What are their living circumstances? (N=220; residential = 91; non-residential = 129)

There were marked differences in the reported living circumstances of the people served by agencies providing residential services, compared to agencies that don't provide such services.

- Virtually all (97.7 %) of the **non-residential** provider staff service clients who live at home with family
- Virtually all (98.9 %) of the **residential** agency staff provide services to clients who live in group homes
- Respondent from both residential and non-residential provider agencies serve clients living in several types of arrangements
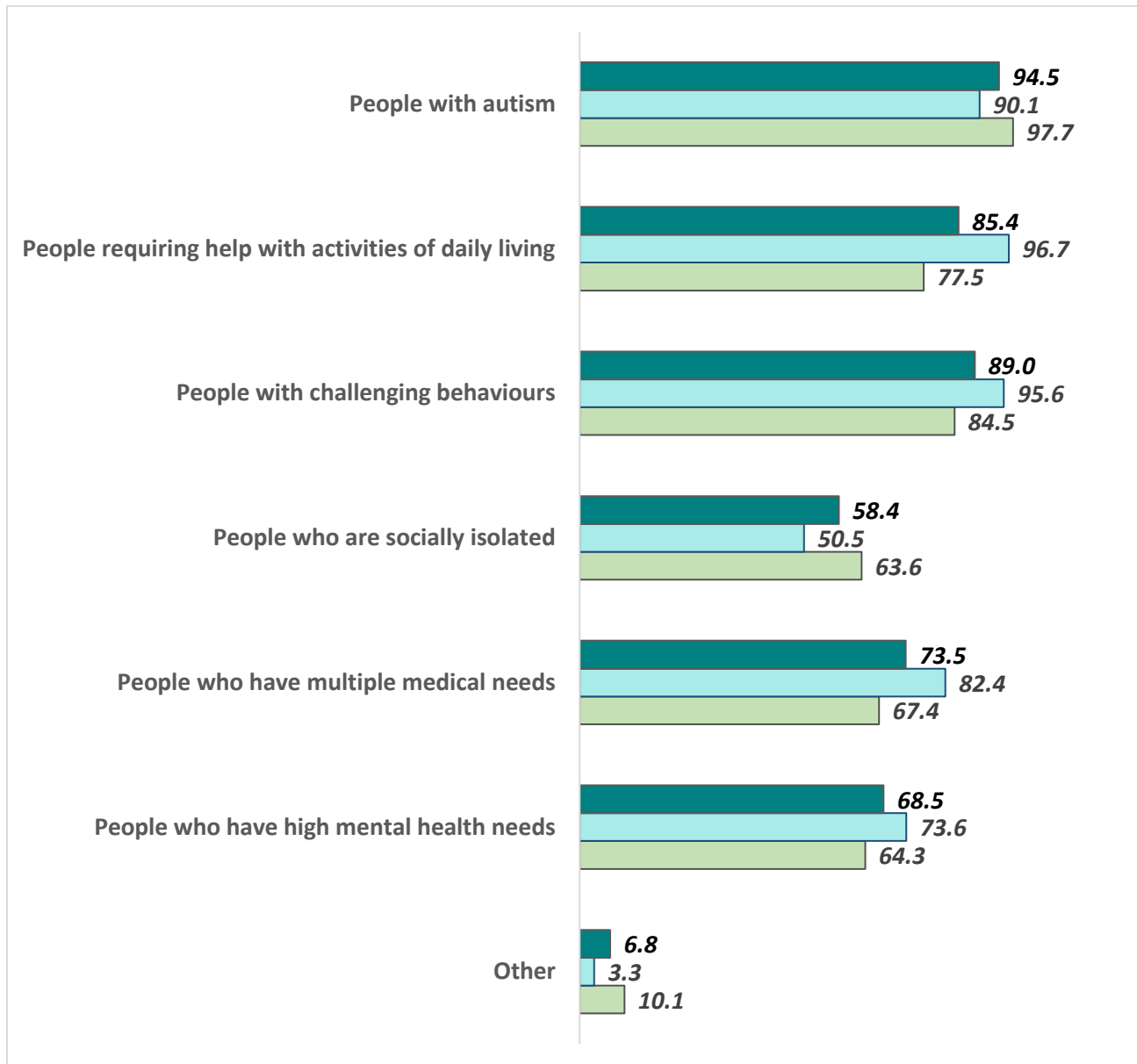
6. Do you serve any of the following special needs groups? (N=220; residential=91; non-residential=129)

- Over 90 percent of respondents serve people with autism (amongst others)
- Virtually all (i.e., over 95%) of the **residential** provider staff support people who need *help with activities of daily living* and those who *display challenging behaviours;* the proportions of **non-residential** settings supporting these clients are somewhat lower (77.5% and 84.5%, respectively)
- Overall, respondents indicate they service clients with a variety of needs

People with autism
94.5
90.1
97.7

People requiring help with activities of daily living
85.4
96.7
77.5

People with challenging behaviours
89.0
95.6
84.5

People who are socially isolated
58.4
50.5
63.6

People who have multiple medical needs
73.5
82.4
67.4

People who have high mental health needs
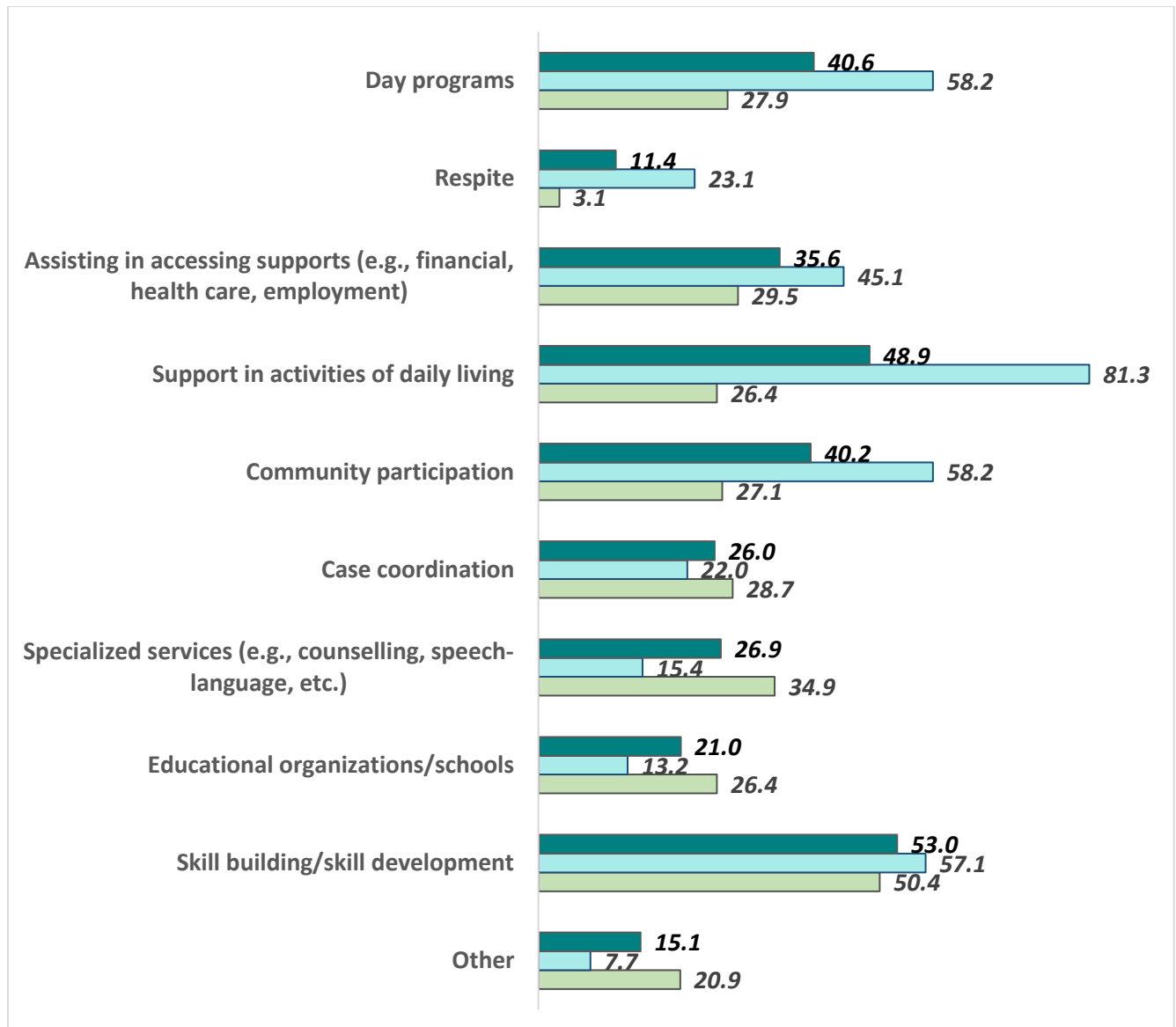68.5
73.6
64.3

Other
6.8
3.3
10.1

Results

7. What is your work with this group? (N=220; residential=91; non-residential=129)

- As expected, staff from residential providers engage in different kinds of work with clients compared to those from non-residential providers
- Respondents from both groups engage in various types of support

Type of Work	Residential	Non-residential
Support in activities of daily living	**81.3**	26.4
Day programs	**58.2**	27.9
Community participation	**58.2**	27.1
Assisting in accessing supports	**45.1**	29.5
Respite	**23.1**	3.1
Skill building/development	*57.1*	*50.4*
Specialized services	15.4	**34.9**
Educational organizations/schools	13.2	**26.4**
Case coordination	22.0	**28.7**

8. **What effects of physical distancing have you noticed on people with developmental disabilities?** (N=220; residential=91; non-residential=129)

- The proportions of respondents selecting the various categories did not appear to differ much between the residential and non-residential organizations in most areas
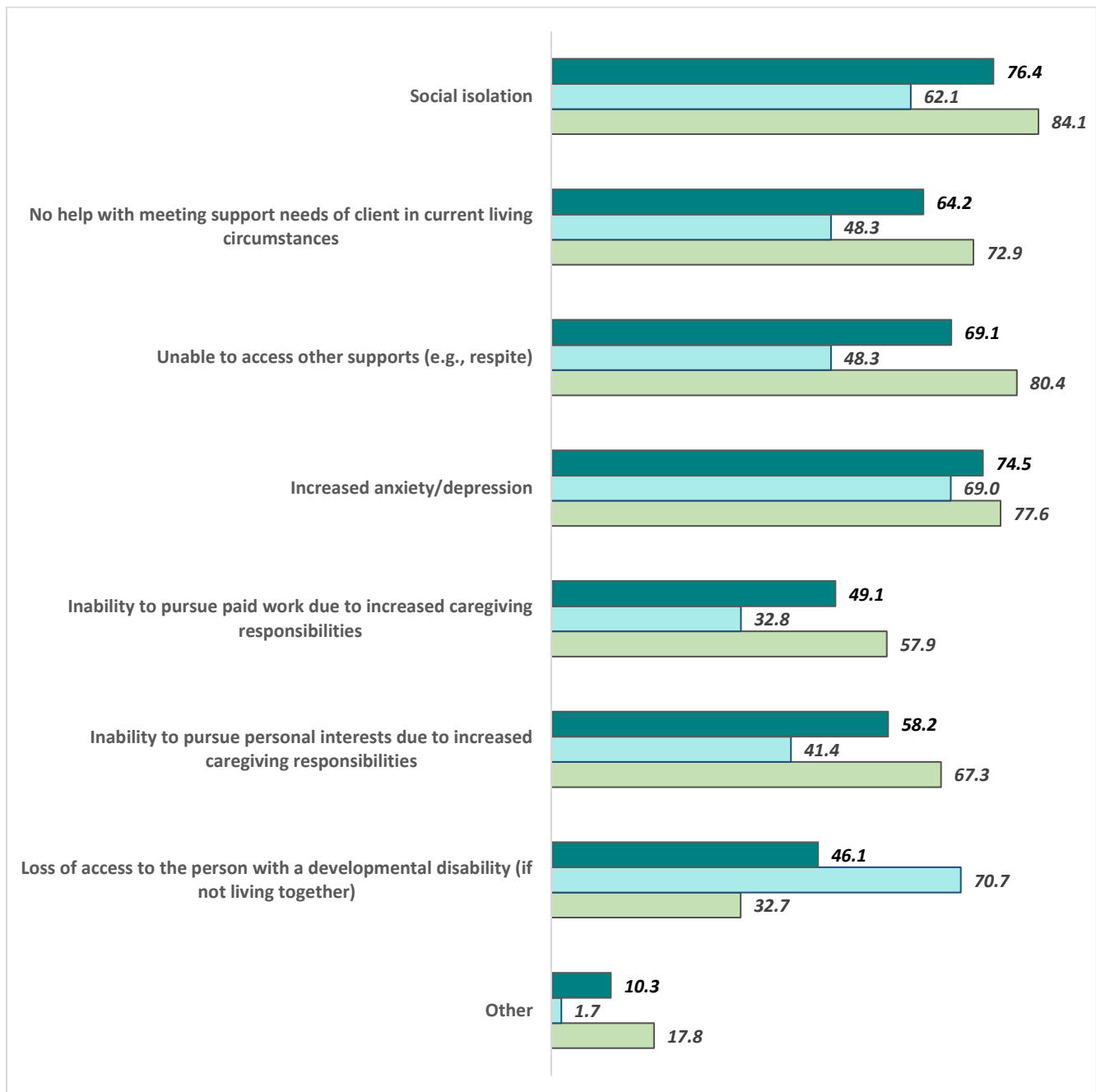- Loss of routines was most commonly indicated followed by social isolation, increased behavioural issues, increased anxiety and depression, and inability to access supports
- One clear exception was 'no help in activities of daily living' (18.7% of residential respondents versus 52.7% of non-residential respondents)

Category			
Social isolation	72.6	68.1	76.0
No help in activities of daily living	38.8	18.7	52.7
Unable to access other supports	66.2	58.2	71.3
Increased anxiety/depression	67.6	72.5	64.3
Increased behavioural issues	68.5	64.8	71.3
Increased health and safety risks	50.7	48.4	52.7
Loss of routines	90.4	87.9	92.2
Loss of employment	32.4	35.2	31.0
Decreased access to healthcare services	52.5	54.9	51.2
Decreased access to support during healthcare visits or stays	37.4	40.7	35.7
Other	15.1	7.7	19.4

Results

10.If you work with informal caregivers, such as family members, what effects of physical distancing have you noticed on them? (N=165; residential=58; non-residential=107)

Effects on informal caregivers	Residential	Non-residential
Social isolation	62.1	**84.1**
Unable to access other supports	48.3	**80.4**
Increased anxiety/depression	**69.0**	77.6
No help with meeting client's support needs	48.3	**72.9**
Inability to pursue personal interests	41.4	**67.3**
Inability to pursue paid work	32.8	**57.9**
Loss of access to the person with a developmental disability	**70.7**	32.7

Social isolation
- 76.4
- 62.1
- 84.1

No help with meeting support needs of client in current living circumstances
- 64.2
- 48.3
- 72.9

Unable to access other supports (e.g., respite)
- 69.1
- 48.3
- 80.4

Increased anxiety/depression
- 74.5
- 69.0
- 77.6

Inability to pursue paid work due to increased caregiving responsibilities
- 49.1
- 32.8
- 57.9

Inability to pursue personal interests due to increased caregiving responsibilities
- 58.2
- 41.4
- 67.3

Loss of access to the person with a developmental disability (if not living together)
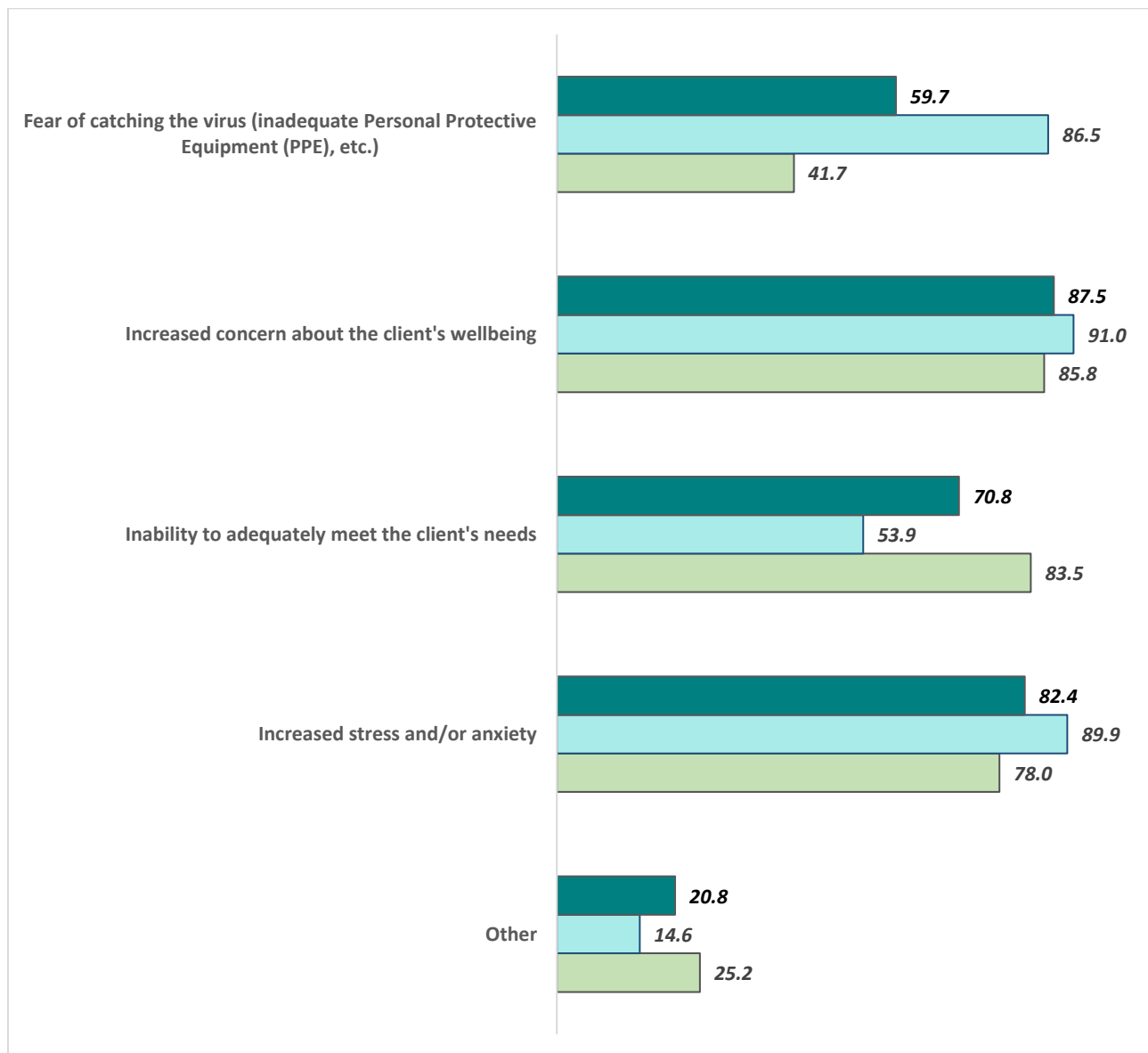- 46.1
- 70.7
- 32.7

Other
- 10.3
- 1.7
- 17.8

Results

12. How has the current situation (i.e., COVID-19) affected you (and/or your staff)?

(N=216; residential=89; non-residential=127)

- Overall, the frequency of respondents indicating impact on staff in all areas asked about was high but there were some apparent differences between staff from residential compared to non-residential providers
- Twice as many respondents from **residential** organizations (86.5%) were concerned about catching the virus (due to inadequate PPE), compared to those from **non-residential** organizations (41.7%)
- A higher proportion of respondents (83.5%) from the non-**residential** organizations reported an inability to adequately meet the client's needs than those from the **residential** organizations (53.9%)
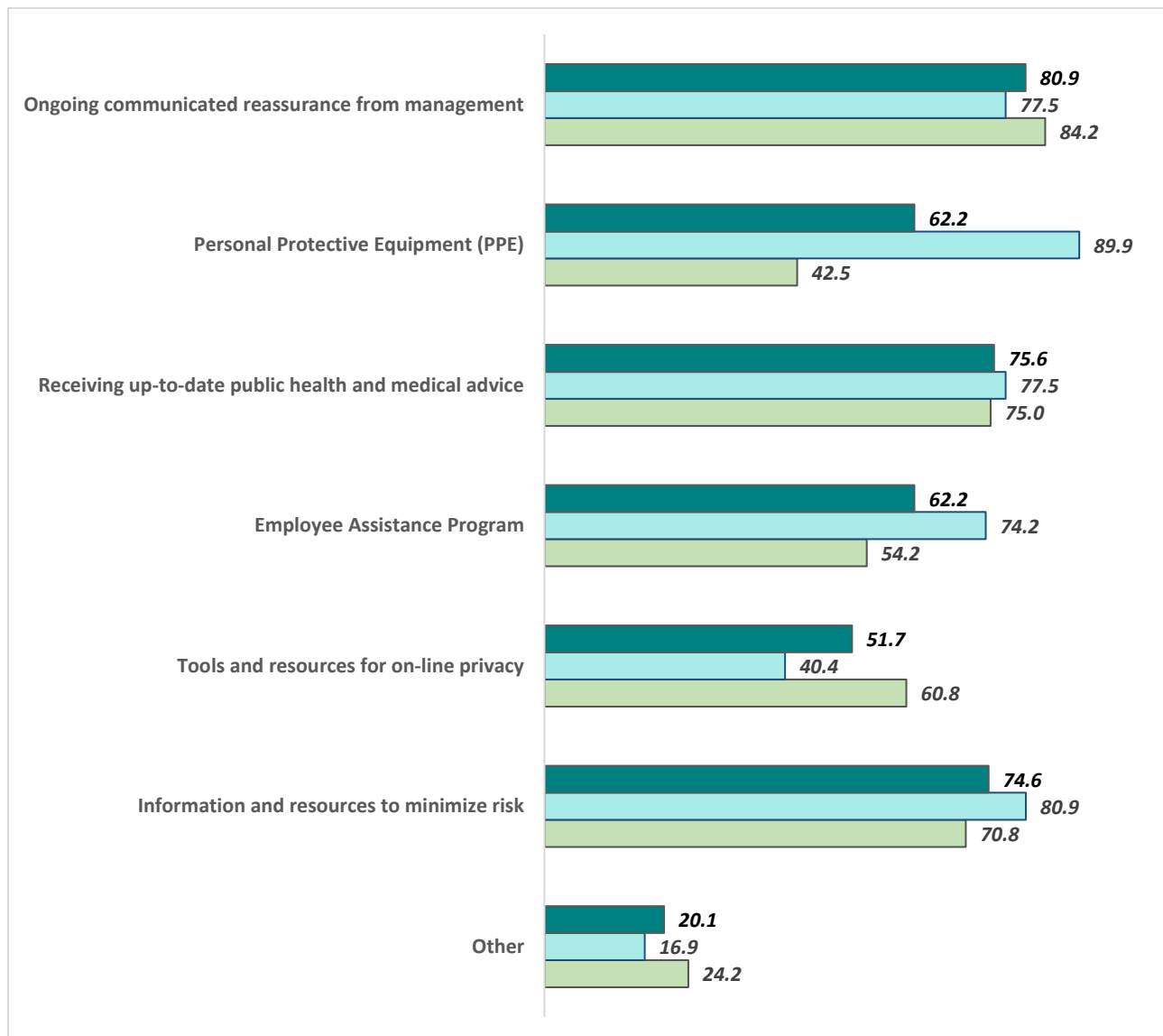

Fear of catching the virus (inadequate Personal Protective Equipment (PPE), etc.): 59.7 / 86.5 / 41.7

Increased concern about the client's wellbeing: 87.5 / 91.0 / 85.8

Inability to adequately meet the client's needs: 70.8 / 53.9 / 83.5

Increased stress and/or anxiety: 82.4 / 89.9 / 78.0

Other: 20.8 / 14.6 / 25.2

13. What supports and resources would help direct client service providers to maintain their health, safety and wellbeing while supporting clients during a pandemic?

(N=209; residential=89; non-residential=120)

- Overall, the most commonly indicated supports and resources, with little apparent difference between groups, were:
    - Ongoing communicated reassurance from management (80.9%)
    - Receiving up to date public health and medical advice (75.6%)
    - Information and resources to minimize risk (74.6%)

- 89.9% of staff from residential providers indicated need for PPE; 74.2% of these staff reported the need for an employee assistance program
- 60.8% of staff from non-residential organizations indicated tools and resources for on-line privacy

14. **Which of the following kinds of supports and resources would help you meet the current needs of your clients (i.e., during this pandemic and physical distancing)?**
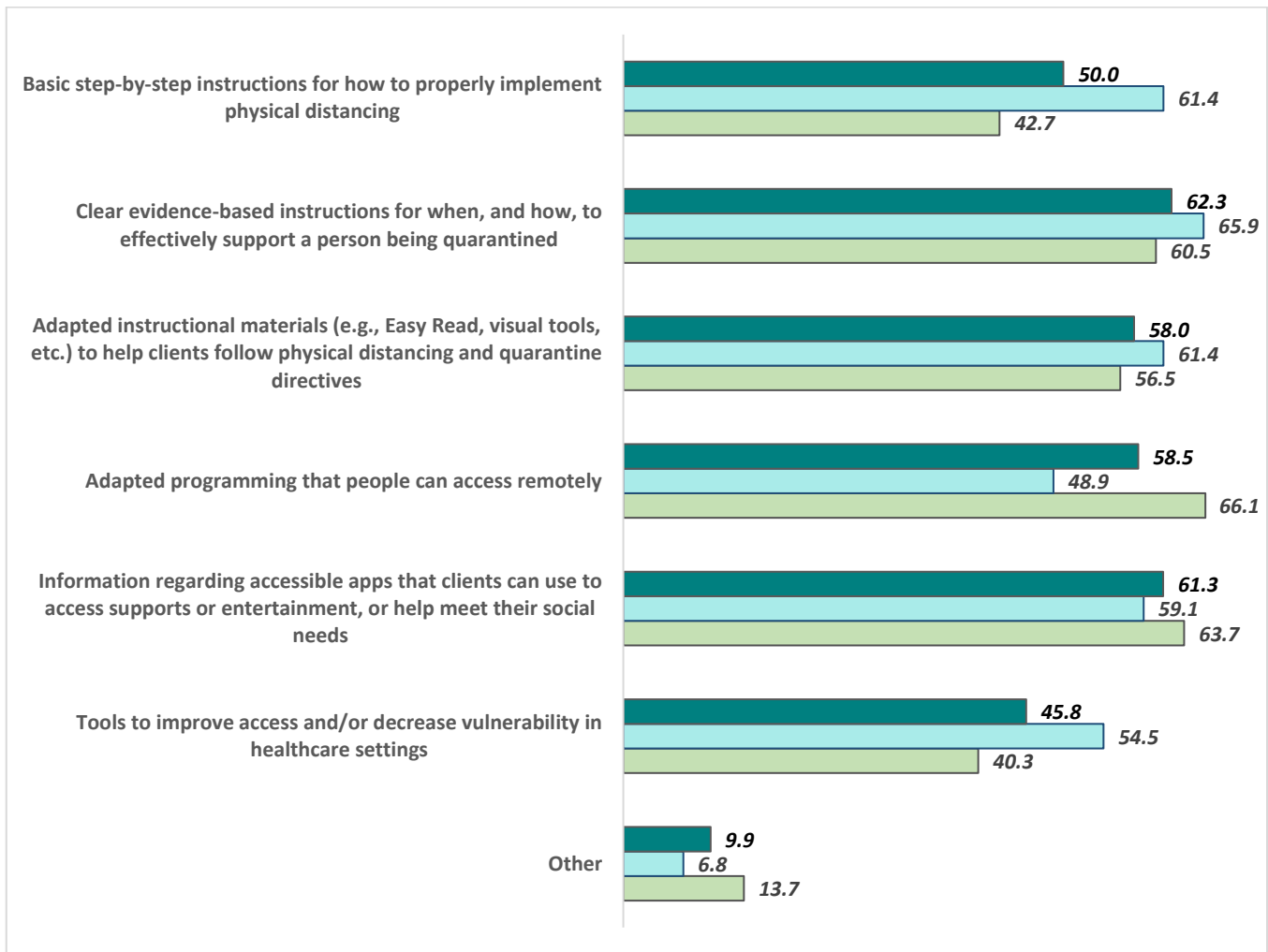(N=212; residential=88; non-residential=124)

To enhance readability, the graph for this question has been split into two parts; responses for the first seven categories are presented in the graph on this page; responses for the remaining seven categories are presented in the graph on the following page.

- Overall, 50% or more of respondents indicated that each of the options would be helpful except for *Tools to improve access and/or reduce vulnerability in healthcare visits (45.8%)*
- Respondents from residential providers most often indicated the following would be helpful: *Timely access to acute medical care to avoid hospital visits (69.3%), Clear evidence-based instructions for how (and when) to effectively support a person being quarantined (65.9%), and Up-to-date information regarding public health initiatives (62.5%)*
- Respondents from non-residential providers most often indicated the following would be most helpful: *Real-time on-line support from social service providers who know the client (70.2%), Real-time on-line supports (e.g., chat/messaging, etc.) (67.7%), Adapted programming that people can access remotely (66.1%), and Information regarding accessible apps that clients can use (63.7%)*

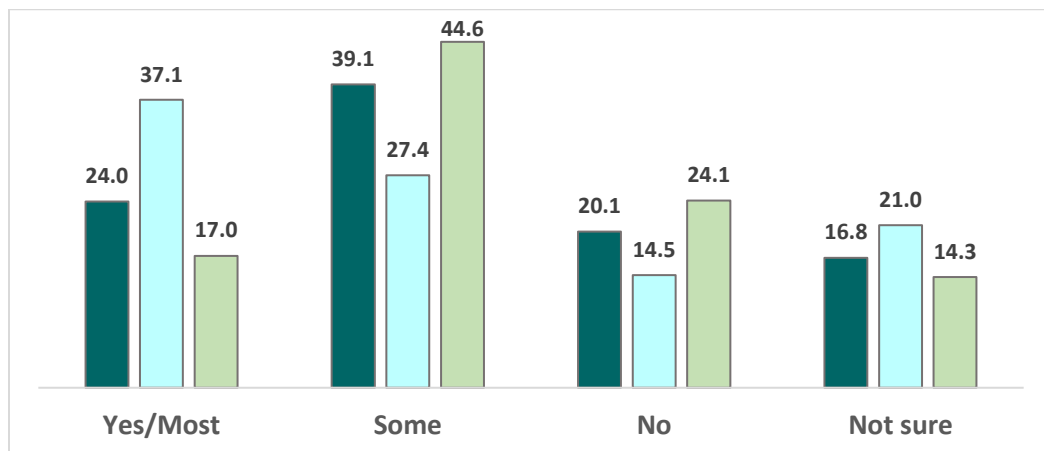| Category	Total	Residential	Non-residential
Real-time telephone supports (Help Line)	58.0	55.7	60.5
Real-time on-line supports (e.g., chat/messaging with general information, etc.)	60.4	51.1	67.7
Real-time on-line support from social service providers who know the client	60.4	47.7	70.2
Real-time on-line support from a healthcare provider who knows the client	55.2	55.7	54.8
Timely access to acute medical care, such as a family doctor or nurse, to avoid going to the hospital	55.7	69.3	46.8
Resources to support the social connection of people with developmental disabilities who are either quarantined or being told to implement physical distancing	59.9	60.2	60.5
Up-to-date information from the municipal, provincial, and federal levels, regarding public health initiatives (e.g., quarantine, physical distancing, testing, etc.)	51.9	62.5	45.2

Question 14, continued.

Basic step-by-step instructions for how to properly implement physical distancing
- 50.0
- 61.4
- 42.7

Clear evidence-based instructions for when, and how, to effectively support a person being quarantined
- 62.3
- 65.9
- 60.5

Adapted instructional materials (e.g., Easy Read, visual tools, etc.) to help clients follow physical distancing and quarantine directives
- 58.0
- 61.4
- 56.5

Adapted programming that people can access remotely
- 58.5
- 48.9
- 66.1

Information regarding accessible apps that clients can use to access supports or entertainment, or help meet their social needs
- 61.3
- 59.1
- 63.7

Tools to improve access and/or decrease vulnerability in healthcare settings
- 45.8
- 54.5
- 40.3

Other
- 9.9
- 6.8
- 13.7

15. **Do your clients and their families have the necessary resources (e.g., personal computer, printer, scanner), and the ability to use them, to submit for Passport or Special Services at Home reimbursements?** (N=174; residential=62; non-residential=112)

Most clients and families do not have the necessary resources to independently submit their expenses for funding reimbursements (results in percentages).

	Yes/Most	Some	No	Not sure
	24.0	39.1	20.1	16.8
	37.1	27.4	14.5	21.0
	17.0	44.6	24.1	14.3

Results

Part Two: Qualitative Results

The majority of respondents provided comments resulting in a rich qualitative data set, complementing and validating the results from the quantitative section. The data was organized into a framework built around the *Acute Effects of COVID-19 and Physical Distancing Requirements*, namely, major disruption to daily life and the loss of access to services and supports. The analysis outlines the *Immediate Effects* of these disruptions on people with developmental disabilities, their families, and developmental services staff and the resulting *Impacts* in the areas of health, mental health and well-being. The *Immediate Effects* might be viewed as mediating or moderating factors that influence the nature and severity of the *Impacts*. The details of this analytic framework are shown in **Appendix 4**.

The interactions between *Acute Effects*, *Immediate Effects* and *Impacts* is taking place within a larger *Social Context* in which people with developmental disabilities are marginalized and the developmental services workforce experiences lack of recognition. The importance of this context and its influence and contribution to negative effects on people with developmental disabilities, family and support staff was often highlighted by survey respondents. Additional day-to-day challenges can relate to language and/or literacy, income, job security, poverty and further marginalization affecting both the person with developmental disabilities as well as their families. This lack of equity affects the sector as a whole to differing degrees, including staff. COVID-19 and its impact has further exposed the increased vulnerability of the clients and the sector.

Effects on People with Developmental Disabilities

For people with developmental disabilities the interruption of regular programming (e.g., day programs, outings, school attendance, etc.) and routine supports (e.g., OT, PT SLP, BT, ABA/IBI, activities of daily living, etc.) has significantly disrupted their routines. In addition, it was reported that people with developmental disabilities are often having trouble understanding the need for

social distancing and having difficulty adhering to social distancing guidelines. These factors have led to numerous impacts on their health and well-being including:

- Increased social isolation due to the loss of direct contact with friends, family members, community, and other natural supports (including key workers) who do not live in the same residence as them
- Increases in challenging behaviours
- Negative emotions – anxiety, depression, boredom, confusion, etc.
- Decreased independence and/or regression in skills
- Increased vulnerability for those living on their own – housing access, food and financial insecurity

Effects on Family and Informal Caregivers

For families living with the person with developmental disabilities, the immediate impact is an increased workload due to round-the-clock care for the person, as well as responsibility for their programming. The severity of this impact depends on how many caregivers are available (e.g., single parent versus more), how many dependents are in the household (and how many have special needs), and whether: the primary caregiver has to work from home; the household income has been disrupted; they have the technology to access on-line resources and supports; there is a language and/or literacy barrier; the living space is very small; and/or the primary caregiver is elderly. Regardless of which factors are at play, primary caregivers now have less time for self-care and no (or limited) access to respite. In general, families are more vulnerable to financial, household, and food insecurity. Many primary caregivers have unmet mental and physical health needs and are further burdened by concerns regarding regression/loss of skills in the person with developmental disabilities; staying healthy themselves so they can take care of their family (including the person with developmental disabilities); and increased challenging behaviours (in some cases). Family members who do not live with the person with developmental disabilities experience increased concern for their loved one.

Results

Effects on Staff

Workers in the <u>residential system</u> are under a great deal of stress. Both their workload and the incidence of challenging behaviours have increased. The lack of appropriate Protective Personal Equipment (PPE) and Infection, Prevention and Control (IPAC) training, coupled with the difficulty of enforcing physical distancing effectively in these environments, has created a high-risk environment for workers and residents alike. Workers in the <u>non-residential system</u> are coping with significant changes to how they provide service. For the most part, they are now working from home and balancing this with full-time childcare responsibilities, making it difficult to perform their normal job functions. Many are feeling anxious about potential layoffs and job insecurity. All workers, whether in residential or non-residential settings, are worried about the safety of their clients, themselves, and their families.

Resource Needs

Respondents identified a number of resource needs to address various *Immediate Effects* of COVID-19 and help alleviate their *Impacts* on health and well-being. These are listed in Table 4B. Additional resources and strategies were identified through extrapolation of the data on the *Immediate Effects* and *Impacts* of COVID-19. Information from the analysis can also be used to identify specific components, objectives and intended outcomes for the planned resources or strategies. Based on qualitative findings as summarized in Appendix 4 and 5 we identified overall areas of concern, contributing issues, and report on suggestions for recommendations embedded in the data.

Results

Goals and Resources/Strategies to Address Identified Needs

1. <u>Enhancing the health and well-being for people with developmental disabilities</u> by enabling staff and informal caregivers to provide support to people with developmental disabilities and enable people with developmental disabilities to support themselves.

- <u>Strategies</u>
  - Increase access to technology as a source of meaningful activity, access to information and social connection - technical and staffing support to help residential clients connect with families and/or friends
  - *Strategies to provide supports that do not involve technology to accommodate people who cannot use, or don't have access to, such technology (e.g., finding creative ways to do safe home visits, face-to-face service)*
  - Raise awareness of social distancing issues for people with developmental disabilities with a variety of sectors such as law enforcement, health care, etc.
  - Helpline – Areas this might address include:
    - Addressing challenging behaviours and mental health issues
    - Establishing new routines and activities
    - Support when planning to go to hospital
    - Support with where to find resources for these various needs, including medical help, ongoing re-assurance available to deal with the confusion of these very different times- explain and re-explain (especially for those living on their own)
  - <u>Tools and resources, policies, procedures, protocols</u> – areas this might address include:
  - Increase activities/establish new routines, reduce boredom
  - Support for dealing with exacerbated behaviours
  - Support to facilitate effective medical appointments for people with developmental disabilities
  - Ensure support staff is available to prevent medical trauma;
  - Testing for COVID-19 when needed, including:
    - Accessible testing strategies (e.g., mobile testing for group home residents, people with mobility issues)
- <u>Financial resources</u>
  - Need for new or additional resources – to keep themselves busy, to communicate – Passport funding allocation – support in accessing these resources when indicated

Results

2. <u>Enhance health and well-being of professional care providers</u>

- <u>Strategies</u>
  - Employee Assistance Program (EAP) to recognize, and provide support for, the increased stress and mental health issues
  - Regular communication – up to date information, re-assurance and support
  - Wage to recognize the increased risk and stress due to the new working conditions
  - PPE availability and training on its proper use, including safety strategies for both staff and clients when behavioural management is needed, including possible restraining
  - Enhanced access to testing when needed
  - Enable client relocation to ensure safety of resident, peers, and workers when needed as well as protocols for reintegration after social isolation

3. <u>Enhance health and well-being of family care providers</u>

- <u>Strategies</u>
  - Increase technological capacity of families to enable them to access:
    - Support staff, therapies, and case management workers
    - Accessible information (e.g., ASL, ESL)
    - Tools and resources
  - Helpline – Areas this might address include:
    - Mental health support for caregivers themselves
    - Information on helpful tools and resources
    - Provide information and referrals for clinical services (e.g., health care, counselling)
  - Access to respite (including support to have time for self-care, shopping)
  - Enhanced and more flexible access to funding and funding reimbursements

  The data also indicated that some people cannot take advantage of technology/telehealth. To accommodate their needs, it is important to find creative and safe alternatives to enable services and supports (e.g., finding creative ways to do home visits, face-to-face service).

- <u>Strategies for family members of people with developmental disabilities in a residential setting</u>
  - Facilitation of contact with a person with a developmental disability, by telephone, video, or other creative means
  - Regular information updates (e.g., re: family member and status of the home) and reassurance for both parties (as indicated and possible

Limitations and Discussion

Limitations of the survey

It is important to consider the following when interpreting the results:

- The survey was limited to the agency staff; a family survey is currently underway
- This survey was asking for perceptions and experiences and did not measure the overall prevalence of the identified issues
- The availability of resources and support for individuals varies widely; solutions and support need to be adapted to individual situations
- Most of the respondents to the survey were from the Toronto area and the results therefore, may not closely or comprehensively reflect experiences outside of this area

Despite these limitations the results provide important information for understanding and addressing the challenges and needs within the developmental services sector during this pandemic.

Discussion

Both the quantitative and qualitative results indicate that the COVID-19 pandemic, the physical distancing requirements and emergency measures have had a large impact on an already vulnerable sector; both the children and adults with developmental disabilities and the people who support them. There appear to be differences between the residential and non-residential settings. However, it is evident that across the sector there is a marked lack of resources to address the escalating needs resulting from the COVID-19 pandemic. Several case-based reports in the media have highlighted the current challenges of clients and caregivers in the sector. These survey findings provide further evidence of system-wide gaps that need to be addressed. The results provide a more detailed and focused identification of specific needs and opportunities for policy and practice recommendations that are applicable both in the short and long-term. Many resources and strategies were identified to address the needs of people with developmental disabilities, those of their informal support networks, and agency staff. In cases where these resources are already being developed and implemented, the report can help inform their specific components, objectives, and intended outcomes. The results are also relevant to long-term planning and the need for advocacy in many areas to minimize negative impacts in future pandemics. These include addressing inequities in areas such as health care, access to technology, and socio-economic status for people with developmental disabilities; and working conditions, wages, and access to proper resources for staff. Findings from the caregiver survey, currently under way, are expected to provide further guidance on support needed and next steps.

Appendix 1. Definitions

Direct client service provider:

Support worker, case management/service coordination, healthcare or mental health professional, etc.

Executive level:

Vice President, CEO, Executive Director

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. Survey Questions

The Toronto Developmental Services Alliance would like to hear from people working in our sector about the challenges encountered, by both those who rely on our services and those who support them, during the COVID-19 pandemic. Agencies are busy trying to collect resources and find new ways to support their clients. The purpose of this survey is to help inform this work.

We are only surveying agencies at this point. Subsequent surveys will be sent out to clients and families. Information will be kept confidential. You, and your organization, will not be mentioned by name.

We are asking for the name of your organization because there may be multiple people from your organization who complete this survey and we would like to keep track of this information. If you choose not to provide this information, it is alright. We would still like to hear from you.

1. What is the name of the organization you work with?

2. In what part of Ontario do you work?
    - 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)

3. What is your role?
    a. Direct client service provider (e.g., support worker, case management/service coordination, healthcare or mental health professional, etc.)
    b. Manager
    c. Director
    d. Executive level (e.g., Vice President, CEO, Executive Director)
    e. Other (please specify)

4. Who are the people your organization supports? Tick off all that apply.
    a. Children
    b. Youth
    c. Adults
    d. Seniors
    e. Other (please specify)

5. What are their living circumstances? Tick off all that apply.
    a. At home with family, who provide support
    b. Independently with a partner
    c. In group homes
    d. In supported independent living (SIL)
    e. Independently on their own
    f. Supported living arrangements (other than SILs)
    g. Other (please specify)

Appendix 2. Survey Questions

6. Do you serve any of the following special needs groups? Tick off all that apply.
   a. People with autism
   b. People requiring help with activities of daily living
   c. People dealing with challenging behaviours
   d. People who are socially isolated
   e. People who have multiple medical needs
   f. People who have high mental health needs
   g. Other (please specify)

7. What is your work with this group? Tick off all that apply.
   a. Day programs
   b. Respite
   c. Assisting in accessing supports (e.g., financial, health care, employment)
   d. Support in activities of daily living
   e. Community participation
   f. Case coordination
   g. Specialized services (e.g., counselling, speech-language, etc.)
   h. Educational organizations/schools
   i. Skill building/skill development
   j. Other (please specify)

8. What effects of physical distancing have you noticed on people with developmental disabilities? Tick off all that apply.
   a. Social isolation
   b. No help in activities of daily living
   c. Unable to access other supports
   d. Increased anxiety/depression
   e. Increased behavioural issues
   f. Increased health and safety risks
   g. Loss of routines
   h. Loss of employment
   i. Decreased access to healthcare services
   j. Decreased access to support during healthcare visits or stays
   k. Other (please specify)

9. Please use this space to describe examples of these effect(S) on **people with developmental disabilities**.

10. If you work with informal caregivers, such as family members, what effects of physical distancing have you noticed on them? Tick off all that apply.
    a. Social isolation
    b. No help with meeting support needs of client in current living circumstances
    c. Unable to access other supports (e.g., respite)
    d. Increased anxiety/depression
    e. Inability to pursue paid work due to increased caregiving responsibilities
    f. Inability to pursue personal interests due to increased caregiving responsibilities
    g. Loss of access to the person with a developmental disability (if not living together)
    h. Other (please specify)

Appendix 2. Survey Questions

11. Please use this space to describe examples of these effect(s) on informal caregivers.

12. How has the current situation (i.e., COVID-19) affected you (and/or your staff)? Tick off all that apply.

   a. Fear of catching the virus (inadequate Personal Protective Equipment (PPE), etc.)
   b. Increased concern about the client's wellbeing
   c. Inability to adequately meet the client's needs
   d. Increased stress and/or anxiety
   e. Other (please describe)

13. What supports and resources would help **direct client service providers** to maintain their health, safety and wellbeing while supporting clients during a pandemic? Tick off all that apply.
   a. Ongoing communicated reassurance from management
   b. Personal Protective Equipment (PPE)
   c. Receiving up-to-date public health and medical advice
   d. Employee Assistance Program
   e. Tools and resources for on-line privacy
   f. Information and resources to minimize risk
   g. Other (please specify)

14. Which of the following kinds of supports and resources would help you meet the current needs of your clients (i.e., during this pandemic and physical distancing)? Tick off all that apply.
   a. Real-time **telephone** supports (Help Line)
   b. Real-time **on-line** supports (e.g., chat/messaging with general information, etc.)
   c. Real-time **on-line** support from social service providers who know the client
   d. Real-time **on-line** support from a healthcare provider who knows the client
   e. Timely access to acute medical care, such as a family doctor or nurse, to avoid going to the hospital
   f. Resources to support the social connection of people with developmental disabilities who are either quarantined or being told to implement physical distancing
   g. Up-to-date information from the municipal, provincial, and federal levels, regarding public health initiatives (e.g., quarantine, physical distancing, testing, etc.)
   h. Basic step-by-step instructions for how to properly implement **physical distancing**
   i. Clear, evidence based-instructions for when, and how, to effectively support a person being **quarantined**
   j. Adapted instructional materials (e.g., Easy Read, visual tools, etc.) to help clients follow physical distancing and quarantine directives
   k. Adapted programming that people can access remotely
   l. Information regarding accessible apps that clients can use to access supports or entertainment, or help meet their social needs
   m. Tools to improve access and/or decrease vulnerability in healthcare settings
   n. Other (please specify)

15. Do your clients and their families have the necessary resources (e.g., personal computer, printer, scanner), and the ability to use them, to submit for Passport or Special Services at Home reimbursements?

16. What are the most pressing needs for advocacy during this time?

17. Can you provide any resources that can be helpful to others? Please provide the details.

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

Appendix 3. Breakdown of 'other' comments for questions 4 through 7

4. **Who are the people your organization supports?** (N=10)

   N/A and 'not applicable' were not counted.

Families and caregivers	3
Non-DS professionals	2
School board staff	1
DS professionals	1

5. **What are their living circumstances?** (N=10)

Homeless	10
Alternate level of care (ALC)	7
Host/Foster Family	4
Long-term care (LTC)	3
Justice system (e.g., jails)	3
Complex Care	1
School	1
At home with senior caregivers	1

6. **Do you serve any of the following special needs groups?** (N=16)

Dual Diagnosis	6
Visual Impairments	3
Deaf, hard of hearing, and deaf-blind	2
People in conflict with justice	2
Physically disabled/mobility issues	2
At-risk Transition-aged Youth	1
Addiction	1

7. **What is your work with this group?** (N=34)

Parenting Support (e.g., resource access) and Education	5
ABA/Early Intervention	5
Intake/Assessment for access	4
Supporting transitions (to hospital, LTC, school, etc.)	2
Support client in school setting	2
Meal Preparation/Feeding	2
Personal Care	2
Employment Training and Supports	2
Clinical support through videoconferencing	1
Counselling	1
Facilitate for clients in the legal system	1
Support Organization	1

Appendix 4. Detailed tables of themes arising from the qualitative analysis

Table 4A: Impacts and Contributing Factors of COVID-19 on People with Developmental Disabilities, Caregivers and Staff

Social/Contextual Factors
Poverty is a reality for many people with developmental disabilities and families (especially families headed by people with developmental disabilities)   - Many families experience challenges with **language and/or literacy**   **Social exclusion** is an issue for many people with developmental disabilities   **Under-employment** and job insecurity   - Marginalization of the Developmental sector and lack of adequate funding (e.g., compensation for workers, no safety net, no pandemic plan)   - Inherent challenges in supporting people with developmental disabilities and their families

Acute Effects of COVID-19 and Physical Distancing Requirements
- Major disruptions to daily life   - No access to **regular programming** (e.g., day programs, outings, school) and the **usual supports** (e.g., OT, PT, SLP, activities of daily living) for people with developmental disabilities   - Residential support workers in the DS sector are considered essential during the pandemic and, as such, are required to provide service in their usual workplace. Many residential support workers hold more than one part-time position, often with different organizations.

Effects on People with Developmental Disabilities	
Immediate Effects	**Impacts**
- Significant disruption to usual routines, services and supports - Not going into community, seeing friends or family - Not accessing health or social services and supports - No supports allowed in hospitals - Funding applications on hold - Loss of access to medication adjustment for increasing or emergent behaviours (and mental health issues) - Difficulty understanding the importance of physical distancing and how to practice it (e.g., 2-metre distance, staying at home) - High risk behaviours at home and in community - Loss of employment - No/insufficient access to technology - to access on-line services and resources for them - unable to submit for Passport reimbursement or access new funding opportunities - Many independent people with developmental disabilities <u>lack</u>: - Natural supports (e.g., an informal support network of family and friends that can rally around them when necessary)	- Increased social isolation - Especially those living independently or in residential settings - Enduring Confusion (due to inability to understand) - Increased risk of catching or spreading COVID-19 due to challenges with adhering to physical distancing - Increase in challenging behaviours - Aggression towards others (e.g., fighting) - High-risk behaviours - Self-injurious behaviours - Property damage - Attention-seeking behaviours - Repetitive questioning/perseveration - Increased mental health issues and negative emotions (e.g., anxiety, boredom, depression, frustration, fear, stress) - <u>Decreased</u> independence - Loss of, or regression in, skills - Adults with developmental disabilities moving back home - Increased vulnerability - Food insecurity - Housing/shelter access (e.g., those leaving the justice system, homeless) - Financial insecurity

Appendix 4. Detailed tables of themes arising from the qualitative analysis

Effects on Families (and informal caregivers)	
Immediate Effects	**Impacts**
- Loss of employment - Work closures during COVID-19 - Due to competing 24/7 caregiver responsibilities - Increased caregiver responsibility to provide support, i.e., providing: - Support to replace lost services and programming - Adults now without day programs and services (including caregiver respite) - May have more than one family member with a developmental disability - Care for other children (including education) - May also need to work from home - Struggle to establish routines, especially for the person with a developmental disability - Adults who have moved back home due to COVID-19 - Struggle to complete basic household tasks such as shopping - Parents may have difficulty, or be unable, to access on-line resources, services, and supports - Many families lack the necessary technology (or cannot use it effectively) - Many families speak English as a second language and/or may have a low level of literacy - Funding applications on hold - Reimbursements may be a challenge - Insufficient resources - Some virtual supports/services are less effective than face-to-face - Activities to engage family members - Educational materials (and support for how to use them) - Cramped living spaces - Many caregivers of adults with developmental disabilities are older, vulnerable and require supports themselves - Caregivers have less (or no) time for self-care - No access to respite (especially if single) - Many are isolated from their natural supports - Family members who <u>do not live with the person with a developmental disability</u> are isolated from that person	- Family caregivers experiencing: - Increase in negative emotion: - Stress, anxiety, depression, fear, frustration, and fatigue - Social isolation - Increased vulnerability - Financial insecurity - Food insecurity - Increased health concerns for primary caregiver(s) - Many have unmet mental and physical health needs - Increased vulnerability of older family caregivers - Families are at increased risk of breakdown/crisis **Family members who <u>do not live with the person with a developmental disability</u> experience** - Increased concern re: safety and wellbeing of family member(s) with developmental disabilities - Increased stress and mental health needs (e.g., anxiety, depression, fear) - Fear of residential staff bringing COVID-19 into the residential setting

Appendix 4. Detailed tables of themes arising from the qualitative analysis

Effects on Residential Workers	
Immediate Effects	**Impacts**
- Many workers are part-time and work at different homes - Lack of appropriate (i.e., health-grade) personal protective equipment (PPE) and knowledge in how to use it - Additional challenges (and workload) due to the absence of the usual supports and programming for residents - Unable to perform regular job functions critical to client safety - Residents do not always adhere to physical distancing rules thereby putting others (including workers) at risk - No wage premium to compensate for the increased risk assumed by the front-line workers	- Social isolation - Increased negative emotions - Stress, fear and anxiety about themselves, or their family, becoming infected - Stress, fear and anxiety regarding their capacity to meet the needs, and ensure the safety, of the residents
Effects on Non-residential workers	
Immediate Effects	**Impacts**
- Significant changes to how workers in the non-residential agencies provide service, resulting in: - Difficulty (or inability) to perform their normal job functions / barriers created due to increased reliance on technology (e.g., lack of access to tech for workers and clients, lack of knowledge in how to use tech - Additional challenges (and workload) due to working from home and, for many, balancing 24/7 childcare at the same time - A lack of information to help workers: - Identify available services (i.e., those that are still open to clients and families) - Access protocols and resources to support crisis response	- Negative emotions (e.g., stress, anxiety, and frustration) - Regarding ability to serve clients - Potential layoffs and job insecurity - The safety of client - Risk of themselves, or their family, becoming infected

Appendix 4. Detailed tables of themes arising from the qualitative analysis

Table 4B: Resources and supports suggested by respondents

<table>
<tr><td align="center">For Clients and Families</td></tr>
<tr><td>

- **Crisis supports for families and clients:**
  - Respite and accessible list of ACTIVE respite workers (with access to pandemic training)
  - Emergency protocols for client/caregiver crises
  - Contact information for crisis support
- **Flexibility in the use of Passport funding to meet current needs:**
  - to buy communication equipment
  - to buy recreational equipment
- **Ensuring equitable access to resources and supports for all clients and families:**
  - Flexible use of Passport funding (see above)
  - Clients need access to the necessary technology to access on-line services and supports
  - Accessible formats (e.g., ESL, ASL)
- **Funding and resources to help parents develop educational activities for their child(ren):**
  - Flexible use of Passport funding (see above)
  - Instructions for parents in how to develop:
    - Educational resources
    - 'Hands on' activities
- **Training for Staff in how to best deliver on-line services:**
  - Models for remote therapy
  - How to provide remote therapy effectively
  - Assistance (or training) with Tele-Health conferencing
- **Provision of reliable, up-to-date information and advice for staff:**
  - One central 'go to' place for information
  - Provision of up-to-date information, especially pertaining to advice, and 'in the moment' support if needed
- **Training for staff on how to deal with clients who do not understand physical/social distancing**

</td></tr>
<tr><td align="center">For All Staff</td></tr>
<tr><td>

- **Resources, Tools, Policies/Procedures, Protocols**
  - Needed in plain language
  - Keeping clients active
  - Dealing with crisis and challenging behaviours
  - For when someone gets COVID
  - Relaxed/flexible requirement for reimbursement (e.g. Passport)
- **Regular information and supportive communication for staff**
- **Helpline**

</td></tr>
</table>

Appendix 4. Detailed tables of themes arising from the qualitative analysis

For Residential Staff
Working Conditions   - Wage increases for residential staff   - EAP   - Modified/flexible work rules for residential staff   - No work at multiple locations for residential staff   **Infection Control**   - PPE   - Training in IPAC and use of PPE   - Nursing support for isolation and quarantine situations
For Non-Residential Staff
Working Conditions   - Accommodations for non-residential staff at home with children   - Childcare   - Flexible work hours   - Job security (non-residential concern)   **IT to support work from home**   - Having the appropriate hardware and software   - Training to use tech   - Tech to enhance privacy   - Tech for families to receive service

Appendix 5. Data coding summaries for individual questions

Questions 8 and 9: Effects of social/physical distancing on people with developmental disabilities

Number of responses:

Question 8 (comment box):   Total=32; Residential=7; Non-residential=25

Question 9 (open-ended):   Total=147; Residential=56; Non-residential=91

Root Cause(s):

The **physical distancing directive** has resulted in:

- Loss of access to **regular programming** (e.g., day programs, outings, school, etc.) and the usual **supports** (e.g., OT, PT, SLP, activities of daily living, etc.) for adults and children with developmental disabilities
- Loss of **direct contact** with friends, family members, and other natural supports (including key workers) who **do not live in the same residence** as them

Mediating/Moderating Factors:

- A **significant disruption to their routines** due to the lack of access to regular programming, usual supports, family (in some cases), and community
- Most people with developmental disabilities have an inherent inability to understand the concept of physical distancing, the importance of it, and why that has necessitated the cancellation of most, if not all, of their structured activities
- This results in **confusion** (which is enduring for many) regarding the lack of routine and physical contact
- Amongst the lost supports are those for **mental health issues** (both pre-existent and those arising from the current circumstances)
    - For example, there is no support for medication adjustments to address emergent behaviours
- Some elective (but needed) medical procedures have been cancelled or postponed
- Social isolation has increased (for many, an exacerbation of an already existing challenge)
    - For example, cancellation of social events (e.g., family birthday parties)
- Many adults with developmental disabilities and families lack the technology to access services and connect socially

Impacts:
- Increased social isolation
    - Especially for those living independently
- Increased challenging behaviours:
    - Aggression towards others (e.g., family members; housemates; group home staff)
    - High risk behaviours (e.g., leaving the home; elopement)
    - Fighting; arguing; conflicts with peers, siblings, staff
    - Repetitive questioning
    - Self-injurious behaviours
    - Property damage
    - Attention-seeking behaviours
- Increased mental health issues:
    - Anxiety (especially for residential settings)
    - Boredom
    - Depression
    - Frustration
    - Fear
    - Stress

Appendix 5. Data coding summaries for individual questions

- Decreased independence:
  - Regression of skills (e.g., social, emotional, physical, communication) due to absence of specialized programs and interventions
  - Increased dependence on staff
  - Independent adults moving back home
- Increased vulnerability:
  - Food insecurity
    - Independent adults with developmental disabilities (including parents with developmental disabilities)
    - Parents of a child with a developmental disability with few, or no, natural supports (especially single parents)
  - Housing/shelter access for independent adults with developmental disabilities
  - Financial insecurity:
    - Loss of employment (affects both adults with developmental disabilities and parents who lose earning opportunities because they are now full-time caregivers)
    - Impaired ability to access funding (both pre-existing and new opportunities)
  - Unmet mental and physical health needs
- Increased risk of crisis (all the elements of a Perfect Storm)
  - Parents and siblings living with children and adults with developmental disabilities are under significant stress
  - Residential support workers, especially as COVID-19 cases appear, are experiencing ever-increasing stress
  - People with developmental disabilities are now without the supports identified to meet their needs
  - Communicating the importance of physical distancing to people with developmental disabilities, in a way they can understand and appreciate the implications, is difficult

Appendix 5. Data coding summaries for individual questions

Questions 10 and 11: Effects of social/physical distancing on informal caregivers

Number of responses:

Question 10 (comment box):   Total=18; Residential=1; Non-residential=17

Question 11 (open-ended):   Total=92; Residential=26; Non-residential=66

Root Cause(s):

The Corona Virus has led to:
- Increased and severe illness amongst many, especially those who are already vulnerable because of other conditions

The resulting Physical distancing directive has resulted in:
- Lack of access to usual service provider for support (e.g., OT, PT, SLP, ADLS, etc.)
- Lack of access to family in some cases
- No access to regular programming (e.g., day programs, outings, school) for the person with a developmental disability)
- A **significant disruption to the routines** of people with developmental disabilities due because of the above

Mediating/Moderating Factors:

- Residential settings have imposed non-visiting policies
    - No social events – for people in residential and non-residential settings
    - No visits of families etc.
- Parents are spending more time supporting their (adult) children, either because they have taken them out of residential settings or day and school programs are not available
    - Caregivers providing lost supports (additional workload)
    - Providing 24/7 care for their child/adult
    - Balancing Work from Home and Caregiving responsibilities
    - Caring for multiple children (with or without special needs)
    - Parents/ caregivers struggle to establish routines
    - Parents struggle to support on-line schooling
    - Limited Resources to keep kids busy
    - Virtual, instead of face-to-face supports can be difficult for parents
    - Concern re: Regression/Skill Loss (social, emotional, physical, communication)
    - Help Accessing Food/Meals/Groceries Families with a child with a developmental disability at home all day; Independent adults)
    - Need for resources and services that are not on-line
    - No access for property repairs (due to CB damage)
- Increased Health Concerns
    - (Caregivers have) less/no time for self-care
    - Aging caregivers are very vulnerable
    - Worry about getting sick and unable to care for child/adult
    - No medication adjustments due to lack of medical access
- Funding
    - Disruption in funding due to office closures, lack of equipment, etc.

- Increased risk of crisis, due to disruptions and lack of usual supports
  - Families (including senior caregivers) are cut off from natural supports
  - Increased stress due to lack of client contact to explain social distancing
- Other:
  - Cramped living spaces
  - Clients with no natural supports

Impacts:

Residential Settings:

- Increased concern of informal caregivers over safety and wellbeing of loved one
- Social isolation from the person with a developmental disability and many other supports
- Increased parental/caregiver stress and mental health needs (because of the worries)
- Separation of family from loved one when a person with a developmental disability stays in residence – no visitors allowed

Both Settings

- Increased health concerns
- Increased stress due to child/resident's increased and significant aggression, SIB, and destruction
- Anxiety
- Depression
- Afraid

Non-residential settings

- Families and caregivers overwhelmed with no respite
  - Caregivers providing lost supports (additional workload)
  - Providing 24/7 care for their child/adult
  - Balancing Work from Home and Caregiving responsibilities
  - Caring for multiple children (with or without special needs)
  - Parents/caregivers struggle to establish routines
  - Parents struggle to support on-line schooling
  - Limited Resources to keep kids busy
  - Virtual, instead of face-to-face supports can be difficult for parents
- Loss of Employment/Income (limited resources) (because person with a developmental disability needs to be home all day
- Frustration
- Fatigue
- Fear of support/respite workers bringing COVID19 into home
- Other Incidental Impacts:
  - Extra food cost due to special diet and travel restrictions
  - Risk of Adoption Breakdown

Appendix 5. Data coding summaries for individual questions

Question 12: Effects of social/physical distancing on staff supporting people with developmental disabilities

Number of responses:

Question 12 (comment box):   Total=45; Residential=13; Non-residential=32

Four main coding areas emerged:

Coding Area	Residential	Non-Residential
Change/loss of normal approach to practice		Yes
Lack of information		Yes
Effects on mental health	Yes	Yes
Human Resource/Labour/Workplace Considerations	Yes	

Non-residential settings:

The **physical distancing directive** has resulted in:

- Significant changes to how workers in the non-residential agencies provide service, resulting in:
  - Difficulty (and sometimes inability) to perform their normal job functions, and
  - Additional challenges (and workload) due to having to work from home and, for many, balance 24/7 childcare at the same time
- A lack of information to help workers:
  - Identify available services (i.e., those that are still open to clients and families)
  - Access protocols and resources to support crisis response

These factors, in turn, have had an impact on staff **mental health and wellbeing**:

- General stress, anxiety, and frustration
- Anxiety specifically regarding potential layoffs and job security
- Fear and anxiety regarding the safety of clients
- Fear and anxiety about themselves, or their family, becoming infected

Residential settings:

Workers in the residential settings are considered essential during pandemics and, as such, have been required to continue to provide service in their usual workplace. Many residential support workers hold more than one part-time position, often with different organizations. This has raised concerns around the following:

- The need to limit a worker to one service provider during the present situation (for the sake of the clients)
- The lack of personal protective equipment (PPE)
- The capacity of this workforce to meet the needs of all residential clients
- The lack of adequate pay to compensate for the increased risk assumed by the front-line workers
- The need for increased employee support during this time

These factors, in turn, have had an impact on staff **mental health and wellbeing**:

- Fear and anxiety about themselves, or their family, becoming infected
- Fear and anxiety regarding the safety of clients

Appendix 5. Data coding summaries for individual questions

Question 13: Resources and supports needed to help staff maintain their health, safety, and wellbeing

Number of responses:

Question 13 (comment box):   Total=44; Residential=15; Non-residential=29

Working Conditions (17 responses)

- Wage increases for residential staff
- EAP
- Modified/flexible work rules for residential staff
  - No work at multiple locations for residential staff
  - Fewer staff in group home
- Accommodations for non-residential staff at home with children
  - Childcare
  - Flexible work hours
- Job security (non-residential concern)

Infection Control (4 responses; residential staff only)

- PPE
- Training in IPAC and use of PPE
- Nursing support for solation and quarantine situation

IT to support work from home (16 responses; non-residential staff only)

- Having the appropriate hardware and software
- Training to use tech
- Tech to enhance privacy
- Tech for families to receive service

Resources, Tools, Policies/Procedures, Protocols (8 responses; source indicated below)

- Needed in plain language (residential)
- Keeping clients active (residential)
- Dealing with crisis and challenging behaviours (non-residential)
- For when someone gets COVID (non-residential)
- Relaxed/flexible requirement for reimbursement (e.g. Passport) (non-residential)
- Mental health wellbeing (non-residential)

Regular information and supportive communication for staff (6 responses)

- Both residential and non-residential

Helpline (1 response)

Appendix 5. Data coding summaries for individual questions

Question 14: Resources and supports needed to help staff meet the needs of people with developmental disabilities and families

Number of responses:

Question 14 (comment box):   Total=23; Residential=6; Non-residential=17

- **Crisis Supports for Families and Clients:**
  - Respite and accessible list of ACTIVE respite workers (with access to pandemic training)
  - Emergency protocols for client/caregiver crises
  - Contact information for crisis support

- **Flexibility in the use of Passport funding to meet current needs:**
  - to buy communication equipment
  - to buy recreational equipment

- **Ensuring equitable access to resources and supports for all clients and families:**
  - Flexible use of Passport funding (see above)
  - Clients need access to the necessary technology to access on-line services and supports
  - Accessible formats (e.g., ESL, ASL)

- **Funding and resources to help parents develop educational activities for their child(ren):**
  - Flexible use of Passport funding (see above)
  - Instructions for parents in how to develop:
    - Educational resources
    - 'Hands on' activities

- **Training for Staff in how to best deliver on-line services:**
  - Models for remote therapy
  - How to provide remote therapy effectively
  - Assistance (or training) with Tele-Health conferencing

- **Provision of reliable, up-to-date information and advice for staff:**
  - One central 'go to' place for information
  - Provision of up-to-date information, especially pertaining to advice, and in the moment support if needed

- **Training for staff on how to deal with clients who do not understand physical/social distancing**

Appendix 5. Data coding summaries for individual questions

Question 16: Most pressing needs for advocacy

Number of responses:

Question 16 (open-text):   Total=141; Residential=54; Non-residential=87

System-Level Needs:

High-level ongoing advocacy:

- Equity for this population (e.g., access to health care, relief programs, support for staff etc.)
- Reflected in fair compensation for residential workers in the developmental sector, especially when providing direct client support during a pandemic.

  "The government should also look into providing assistance to part-time workers who have no benefits and are forced to go to work because they fear they might lose their jobs if they don't show because their organization is not considered to be non-essential which means they don't get paid if they don't show up for work."

Access to health care practitioners and facilities:

- Equal access to health care and support
- Ability for someone to accompany people with developmental disabilities into the healthcare setting to facilitate for them and mitigate their separation anxiety

Funding for clients and families (ensuring access, continuity, and flexibility):

- Expand the criteria for allowable Passport expenses (e.g., recreational and arts activities, iPads to connect to on-line services and supports)
- Provide the necessary support to clients and families so they can access (and ensure continuation of) funding opportunities
- Accessing SERC and other emergency financial support when home to look after the person with a developmental disability
- Support those who were in process of getting funding, but are now on hold
- Advocate for assurance that families and clients will not lose access to funding due to interruptions caused by the COVID-19 pandemic

Advocacy for Families in Crisis:

Support to help families care for the person with a developmental disability:

- In-home supports to:
  - Help deal with complex needs and challenging behaviours
  - Help establish a routine
  - Provide meaningful activities to engage the client
  - Funding to secure these supports

Support for the family caregivers themselves:

- Respite
- Access to mental health support
- Childcare (to support those working from home)
- Peer support

Appendix 5. Data coding summaries for individual questions

Service providers to connect with families to offer support of various types:

- Maintain a connection with the family so they know they are supported
- Identify issues and ensure safety
- Mental health outreach/support
- Ensure families and clients know about resources (including those that are specific to COVID-19)
- Ensuring that privacy is maintained during on-line services

Ensuring families and clients have the technology required to connect socially and to access resources:

- Equipment (or funding to purchase it)
- Affordable (or free) and reliable internet access
- Training for families and clients in how to use technology to access on-line resources and connect socially
- At minimum, ensure all families and clients have communication devices (e.g., iPads, cell phones) to maintain social connections with family and friends
- Ensure that clients have the technology/support that they can use – many not comfortable using technology

Advocacy for Residential Support Workers

How to support residential staff in dealing with a pandemic:

- Availability of healthcare-grade PPE for all staff, including part-time workers
- Training in how to properly use the PPE
- Information to support the training (this, and both points directly above, are a requirement of Occupational Health and Safety in Ontario)
- Protocols for implementing physical distancing with clients
- Availability of COVID-19 testing
- Pandemic plans that include
  - Protocols for the support and care of clients who test positive and require isolation
  - Safe alternate living arrangements for these clients
  - An easy-to-access on-line repository of reliable and up-to-date information on COVID-19

Fair financial compensation for residential workers in the developmental sector:

- Front-line residential workers providing support for vulnerable populations, including people with developmental disabilities, are undervalued and underpaid
- Many front-line workers do not have full-time positions and therefore may not have benefits packages
- During a pandemic, these workers are considered essential
- In general, workers' salaries ought to be increased
- Specifically, there ought to be a wage premium for workers providing direct support to clients who test positive for COVID-19

Other forms of support for workers during a pandemic:

- Employee Assistance Program providing support for employee mental health and wellbeing
- Child care support for employees who have to work during a pandemic (if schools and daycares are closed)

Appendix 5. Data coding summaries for individual questions

Question 17: Resources that can be helpful to others

Number of responses:

Question 17 (open-text): Total=56; Residential=24; Non-residential=32

Helpful websites identified by respondents:

Community Living Toronto Coronavirus updates:

https://cltoronto.ca/coronavirus/

Community Living Toronto staff resources:

https://cltoronto.ca/covid-19-staff-resources/

Surrey Place website (COVID-19 resources):

https://www.surreyplace.ca/resources-publications/coronavirus-updates-resources/#about

Autism Ontario website (COVID-19 resources):

https://www.autismontario.com/list-resources-help-us-through-covid-19

Developmental Disability and COVID-19 (blog):

https://www.empoweringability.org/covid19/

Connectability:

https://connectability.ca/en/

Vulnerable Persons Registry:

https://www.torontopolice.on.ca/vulnerable-persons-registry/

Resources to help parents support their child's learning during quarantine:

COVID-19 time capsule:

https://withgia.com/wp-content/uploads/2020/04/2020-covid-19-time-capsule-sheets-laura-share.pdf

Scholastic "Learn at Home' modules:

https://classroommagazines.scholastic.com/support/learnathome.html

GoNoodle – Movement and Mindfulness Activities for Kids:

https://www.gonoodle.com/

KidsHelpLine:

https://kidshelpphone.ca/

Starfall:

https://www.starfall.com/h/

Appendix 5. Data coding summaries for individual questions

Question 18: Is there anything you want to add that we have not included in this survey?

Number of responses:

Question 18 (open-text):   Total=51; Residential=26; Non-residential=25

Financial reimbursement and working conditions for staff:
1. Recognition of the issues of part time staff – no benefits and working in more than one organization
2. Danger pay or increased numeration because of risk

Recognition and support from management for staff:
General recognition
1. Staff face the risk, while management does so much less – honest recognition for the work performed
2. Compassion for frontline
Additional Supports/Training needed:
1. Adequate PPE and training
2. Support and training on dealing with staff in quarantine who have behavioural problems
3. Understanding of the challenges to maintain social distancing in small spaces and keep clients engaged
4. Dealing with clients who do not adhere to the rules

Mental health/anxiety of staff
1. Fear of job-loss
2. Fear of bringing virus home
3. Anxiety

Clients' access to resources/support
1. Many clients illiterate and unable to access information resources and complete required forms: we need to find a way to help them over the phone
2. Ensure communication needs of clients are met: information and social connections
3. Clients have additional financial needs

Government regulations:
1. Access to emergency benefit for people who find their jobs too high risk
2. Balancing mental health and need for physical distancing