An Evaluation of the Sector Pandemic Planning Initiative (SPPI)

A MARCO Study Report

August 2022

MAP Centre for Urban Health Solutions
UNITY HEALTH TORONTO
UNIVERSITY OF TORONTO

About the MARCO Study

The MARCO project is evaluating how local efforts responding to the COVID-19 pandemic serve people experiencing marginalization, and how these interventions can be improved. Changes in society to control the pandemic have affected everyone, but they place a particularly heavy burden on people who are marginalized.

About this Report

This report presents the findings of the Sector Pandemic Planning Initiative (SPPI) evaluation.

The views contained in this report do not necessarily express the views of any MARCO community partner, funding agencies, MAP, St. Michael's Hospital, Unity Health Toronto, the University of Toronto, or any other organization with which MARCO authors or project team members may be affiliated.

Suggested Citation

Isaacs B, Durbin A, Ahmed U, and Holness DL (Co-lead Authors), Conrad-Ferguson C, Warsame K, Ren P, Nisenbaum R, Lunsky Y, Firestone M, Bayoumi AM. An Evaluation of the Sector Pandemic Planning Initiative (SPPI) Initiative, A MARCO Study Report. Toronto, Ontario: MAP Centre for Urban Health Solutions, St. Michael's Hospital. November, 2021. Available from https://maphealth.ca/wp-content/uploads/SPPI_finalreport.pdf

Acknowledgements

MARCO gratefully acknowledges funding from: the Temerty Foundation and the University of Toronto through the Toronto COVID-19 Action Initiative; the University of Toronto's Faculty of Medicine Equity, Diversity, and Inclusion fund; and the St. Michael's Hospital Foundation.

We would like to acknowledge the following people for their support: Don Walker and Ursula Rehdner for their overall guidance and input into all aspects of this project including but not limited to, development of the SPPI logic model that is guiding this work, development of the survey, recruitment of participants and editing of this report. We would also like to thank Mia Tremblay, Malcolm Bernstein and Martha McGrath for their input in developing the SPPI logic model and Veronica Pepper and Cassandra Fitzgibbon for input into shaping the overall project.

Land Acknowledgement

We acknowledge the sacred land on which MAP and Unity Health Toronto operate. It has been a site of human activity for 15,000 years. This land is the territory of the Huron-Wendat and Petun First Nations, the Seneca, and most recently, the Mississaugas of the Credit First Nation. The territory was the subject of the Dish With One Spoon Wampum Belt Covenant, an agreement between the Iroquois Confederacy and Confederacy of the Ojibwe and allied nations to peaceably share and care for the resources around the Great Lakes. Today, the meeting place of Toronto is still the home of many Indigenous people from across Turtle Island and we are grateful to have the opportunity to work in the community, on this territory. We are also mindful of broken covenants and the need to strive to make right with all our relations.

Contact Us

Website: maphealth.ca/marco Email: marco@unityhealth.to

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The Developmental Services Sector

The Developmental Services (DS) sector provides care and support to individuals living with developmental disabilities (DD). Services include residential (e.g. group homes) and respite care, day programs, clinical services and support, case management and service coordination. Agencies within the DS sector have collaborated prior to the COVID-19 pandemic, such as in the Toronto Developmental Services Alliance (TDSA). With the onset of COVID-19, organizations recognized the need for a coordinated response to help them adapt to the restrictions necessitated by the pandemic. As such, the Sector Pandemic Planning Initiative (SPPI) was created to develop a suite of resources for use by the DS sector with a purpose to address safety, labour, policy, legal, ethical and service delivery issues as well as training and support needs. The SPPI developed a variety of information and position documents alongside tools and training resources that were distributed widely. The outputs were intended to be used by DS agency management, staff, as well as adults living with DD and their families to mitigate the negative impacts of the pandemic.

What was evaluated?

We evaluated the SPPI. Four questions were posed:

- How were DS agencies, staff and clients impacted by the pandemic?
- How are DS staff and adults living with DD marginalized and were they further marginalized during the pandemic?
- How did DS agency pandemic preparedness and response change over the course of the pandemic?
- Was the SPPI helpful in supporting agencies during the pandemic and if so, how?

What were the key findings?

The evaluation included both quantitative and qualitative methods. Online surveys were completed by 53 frontline staff and 35 management staff (residential and non-residential staff), between April and June 2021. Virtual interviews were conducted with 14 management staff and 10 frontline staff between July and October 2021.

How were DS agencies, staff and clients affected by the pandemic?

Impacts on Services

Residential Program Operations

Residential programs continued to operate but had to modify operations substantially. Approximately one month into the pandemic, employees were limited to a single place of work, as opposed to holding jobs at multiple organizations. Agencies had to implement Infection Prevention and Control (IPAC) and public health measures, requiring social distancing and the use of appropriate personal protective equipment (PPE). In addition, non-essential visiting (in many cases the resident's family members) was stopped, although eventually returned with public health restrictions in place.

Day and Community Based Services & Programs

Initially, almost all day and community based services and program activities stopped, such as client employment as well as social and recreational activities. Many transitioned to virtual programming, although some clients and staff experienced challenges, such as confusion and

uncertainty during this shift. Some of the programs and services re-opened to in-person for a short period of time between wave 1 and 2 of the pandemic, but closed again when cases increased and public health measures were re-instituted.

Impacts on Clients

Clients faced disruptions in their routines, including loss of activities, loss of regular visits with family and friends and shifting to virtual programming. Some clients living in residential settings found it difficult to understand social distancing measures and the importance of using PPE. When non-residential services transitioned online, some clients did not have devices to access virtual programming. Among those with adequate technology, some managed well with this transition while others experienced challenges, disengaged and no longer participated in programming.

Public health measures and restrictions also impacted medical appointments; some appointments were held virtually while some continued in-person. As public health restrictions did not permit people to bring family members or supports to accompany them to their medical appointments and hospital visits, this resulted in distress for some clients. Some clients also encountered challenges when attending their COVID-19 vaccine appointments.

These disruptions caused stress and isolation and resulted in a variety of behavioural changes and mental health issues among clients. Staff reported that some became reclusive, scared and some who had made considerable progress experienced setbacks. As clients encountered more stress, anxiety and depression also increased. Some clients expressed anger about the changes in programming and some experienced these changes as traumatic.

Families that were used to attending day programs that were discontinued began to struggle to support clients that were now always at home and thus needed additional caregivers, external supports and resources. While many of these clients had funding to cover their participation in day programs, switching to using that money to support clients at home was challenging.

Impact on staff

At the beginning of the pandemic. DS staff encountered uncertainty. They described the initial experience as organized chaos but remarked on the improved sense of community and confidence they felt throughout the pandemic.

There was substantial job disruption. This included changes in work location, such as some day program staff redeployed to residential settings and working longer shifts. Requirements for staff to work only at one employer and to discontinue the use of temporary agency staff led to staff shortages and redeployments. These changes created challenges with staff in arranging schedules with their partners and family members and around child and elder care responsibilities. It was also challenging in some instances to take time off and to schedule vacations.

Along with shortages and scheduling challenges, staff who were deployed to residential settings noted this was not the work they signed up for. The work that staff had to do in the homes was physically tiring. Staff were exhausted with cleaning, wearing PPE, and attending to client care.

Similar to client experiences, some staff struggled with using technology. Some had major issues with setting up virtual activities and some found learning new technology to be draining. Most described feeling “Zoomed out” and had “Zoom burnout.”

Day programming and community services staff were impacted by the loss of contact with their clients. In some instances, they did not know what was happening with their clients and they missed the human connection. These various impacts had effects on staff mental health; staff described having problems staying engaged and many noted burnout. Regarding COVID-19 itself, there was also lack of knowledge about the virus, concerns about the vaccines and vaccination requirements, and

fear of getting infected and spreading COVID-19 to their families.

How are DS staff and adults with DD marginalized and were they further marginalized during the pandemic?

Our interview participants discussed how people living with DD and the workers who support them experience marginalization, as well as marginalization in the overall DS sector. Clients were described as experiencing marginalization based on living with a developmental disability and, as a result, experiencing stigma, isolation, health inequities, and poor access to healthcare, other services and the COVID-19 vaccine. They were also described as belonging to other marginalized groups including those with physical disabilities, mental health challenges, living in poverty and identifying as 2SLGBTQ+. The DS work force was described as being comprised of people who earn low wages and people who are racialized, and lastly, having a large proportion of single mothers. This intersectionality was seen as particularly true for staff who worked in residential settings.

Interviews illuminated how these pre-existing inequities and experiences of marginalization were exacerbated by the COVID-19 pandemic. Participants indicated that people living with DD, as well as staff and service providers who support them, are at a higher risk of experiencing a greater degree of negative impact as a result of the pandemic. Both clients and staff in the DS sector are at a higher risk of contracting COVID-19; the risk for people living with DD is increased by poorer overall health and living in congregate settings. The risk for residential workers was increased by working in congregate settings, having to travel by public transit and living with others also having to travel because they could not work from home.

Interview participants made an important distinction between people living with DD living in group homes versus those living in the community. Those living in the community were seen as facing a different set of challenges. Interviewees described financial difficulties faced by people who suddenly required full-time support due to the cancellation of day programs but not having the financial means to obtain such support.

The DS sector was described as being ignored by the government. While a lot of public and government attention was being paid to the needs of long-term care, similar issues in DS group homes initially were not addressed. Participants felt that people living with DD were generally being devalued by society. A lot of advocacy work by stakeholders within the sector was required to bring government attention to this population experiencing marginalization.

Agencies in the DS sector have responded to the various components of marginalization and the aforementioned challenges in several ways. Pandemic wage enhancements were provided and one interviewee indicated that residential workers at their agency were offered hotel rooms paid for by the agency with meal reimbursement to reduce the risk of spreading COVID-19 to their family members. In some agencies, committees were formed to address issues of discrimination and inequities in the work environment. Staff training focusing on equity and diversity was provided. Interviewees also spoke about policies and procedures to address situations involving discrimination in the workplace. Some agencies also have dedicated services and supports for people with DD and their families who belong to other marginalized groups, such as new immigrants. Some interviewees indicated that while work was being done to address marginalization of clients and the workforce, progress was slow and more needs to be done.

How did DS agency pandemic preparedness and response change over the course of the pandemic?

Interview participants indicated that initial agency responses to the pandemic were chaotic but as time went on, the policies and procedures were put into place and agencies became experienced in dealing with pandemic issues. This observation was supported by survey findings that found both management and staff reported an increase in the rating of pandemic preparedness with each wave.

Similarly, staff reported the increased availability and use of PPE during the pandemic. A variety of supports for clients and staff were also implemented.

Supports for clients

Most day programming activities, if they continued, were offered virtually. Technical support was a critical component of establishing virtual programming and clients were offered iPads and tablets, as well as support in how to setup and use their new devices. Additionally, supporting documentation such as activity workbooks were also adapted to meet virtual programming needs.

Agencies also increased programming options. Agencies and staff recognized the importance of keeping clients engaged, connected and busy, whether at their own home or in residential settings. Programs focused on being flexible to try to address various client's interests and needs and staff facilitated virtual activities such as dance, exercise and science experiments.

Many agencies increased staffing and external resources to further support new programming initiatives and participants. When possible and permitted under public health guidelines, staff provided individual, support to participants in the community with outdoor activities. Occasionally, these activities included both participants and their caregivers or family members, to enhance socialization for clients and their families. During community visits staff were also provided flexibility in programming and support they provided to clients in the event of minimal access to public washrooms or poor weather.

To maintain a sense of connection with clients and families, agencies focused on increased communication. This included keeping families informed through webinars, weekly email announcements as well as offering direct email communication with agency executives or management. Residential settings scheduled regular resident meetings to communicate about health and safety protocols. Many noted that the use of social stories was particularly helpful in explaining information regarding COVID-19 infection, transmission, and vaccination to clients and their families.

To support clients, particularly those in residential settings, increased health supports were established. This included necessary health and safety supplies such as PPE, the creation of health teams with medical check-ins, medical care and help with understanding and receiving the COVID-19 vaccine. Some staff explained how pandemic responses and programming also need to be trauma informed in order to effectively meet client needs.

Agencies were also given access to increased sector funding as the Ministry of Children, Community and Social Services (MCCSS), established the COVID -19 Residential Relief Fund to provide organizations more access to computers and equipment. Additionally, more flexibility in moving funds across portfolios was allowed. These increases enhanced social and recreational programming support for clients. *Passport funding* also increased and was expanded to include digital equipment which further supported clients with virtual programming and maintaining social connection.

Supports for staff

In response to the COVID-19 pandemic, supports for staff were either newly established or enhanced across DS agencies. These supports were related to pay and benefits, health and wellness, alongside support for program delivery. These results were found in both the survey responses and interviews.

Financial support included wage increases from employers and government, benefits and supports, specifically related to COVID-19 exposure and infection. Some people who did not qualify for the increased pay were allowed to work fewer hours. Many agencies extended sick days to part time staff, who were not previously eligible for paid sick time. In many cases, there was more flexibility for staff to take sick days; staff could use sick time due to COVID-19 exposure or, if they wished, to take a mental health day.

There were various responses to scheduling. Some staff noted that there were accommodations made to support family schedules and child care needs. Some agencies elected to increase their full time employee roster and switched part time employees to full time status, which then provided them with benefits that they did not have access to before. Staff shortages and lack of relief staff led to challenges with scheduling sick days and vacation time. In addition to paid time for isolating, some agencies provided staff the option of staying in a hotel if they did not want to go home with the concerns about infecting family members.

Supports for mental health and overall wellness were also prioritized. Agencies emphasized the available Employee Assistance Programs (EAP), and they were often extended to all staff, regardless of full time, part time, or relief status. Many agencies arranged virtual training and sessions on burnout, mindfulness and self-care, yoga and meditation, more frequent check-ins, and team building exercises. Organizations also demonstrated their appreciation of the staff and the work they were doing with parties, gifts, care packages, gift cards, helping with groceries, and food drives.

The provision of technical devices and support was also critical to supporting staff. This included providing staff with cell phones and laptops to use when working remotely.

Facilitators to adjusting to the pandemic

A key facilitator to adjusting to the changing programming needs of the pandemic was having previous experience with digital programming. Some agencies successfully facilitated change by creating a team to manage pivoting to online and modified service delivery.

Barriers to adjusting to the pandemic

Initially, uncertainty about how long the pandemic would last delayed the transition to virtual programming for some agencies and was a barrier to adjusting to the pandemic. Another barrier to adjusting to the impacts of the pandemic was the evolving nature of the pandemic, which led to multiple directives from government. Varying directives and inconsistent messaging between different public health units and the Ministry of Health was especially challenging for agencies who provide supports in more than one public health unit.

Was the SPPI helpful in supporting agencies during the pandemic and if so, how?

Survey responses from management respondents found 77% reported SPPI being helpful or very helpful. Interviewees also spoke positively about the information and resources provided by the SPPI, describing them as valuable in several ways, using phrases such as time saving, trustworthy, and helpful. The majority of management interviewees indicated that their organizations shared SPPI resources with staff, clients and families. Interviewees identified the following specific resources as being used within their agencies: social stories, re-opening documents, single employer guidelines, and webinars. SPPI resources were useful contributors to policy development. Areas in which the SPPI was specifically stated to be helpful were PPE procurement, IPAC, and vaccination rollout. Interviewees indicated belonging to a network provided easy access to others to consult with on questions, and to understand what other organizations were arranging. Finally, the SPPI had impact beyond developmental services and it was used as a model by the MCCSS for other sectors to follow.

What are the recommendations moving forward?

1. The SPPI was an effective approach to rapid pandemic responses and preparedness. We recommend other sectors working with communities who experience marginalization consider establishing similar networks with agency-based leadership, in partnership with public health. Networks can work on a variety of system issues, including future pandemic preparedness, and will prepare these sectors for future events of this magnitude.

2. Many agencies were not aware of the recommendations arising after the 2003 Severe Acute Respiratory Syndrome (SARS) outbreak. Agency networks should make pandemic and emergency preparedness an on-going area of concern so that information is preserved and up-to-date. The SPPI is actively putting together a pandemic preparedness field guide for agencies. This should be revisited on a regular basis, perhaps annually, after the pandemic, and updated as needed to ensure the knowledge contained within is not lost or becomes obsolete.

3. Attention should be paid to developing and continually updating the capacity of all agencies to deliver virtual supports to clients both during the pandemic and once the pandemic is over. While agencies can make this a priority, assistance from government and other system level entities should also be a priority. Government could consider dedicated budget lines, training programs, system wide infrastructure, and funding research and development. Agencies should consider continuing at least some on-line programming after the pandemic. To do so, they will need to ensure their staff and clients have access to sufficient and reliable internet networks and connections. Both staff and clients will also require appropriate and effective technical training.

4. Public Health and government should recognize inequities and marginalized populations and factor these into pandemic preparedness and responses. They should actively seek participation in system level committees from representatives of such sectors. Representation should come from people with lived experience, family members as well as agencies. As part of this strategy, both government and Public Health should also seek out and recognize groups such as the SPPI who work on pandemic preparedness and advocate for specific populations. At the same time, these sectors and their agency-based networks should advocate to be active participants in sector level health and public health initiatives.

Introduction

On March 17th, 2020, a state of emergency to address the COVID-19 pandemic was declared. This initiated public health restrictions such as social and physical distancing, lockdowns, service closures and stay at home orders. The introduction of these public health measures led to the temporary closure of some health and social services, creating additional barriers to access.

People living with developmental disabilities (DD) experience greater health and social inequities than members of the general population.[1] These inequities were amplified once the COVID-19 pandemic was declared and public health measures put in place on March 17th, 2020.[2-4] People living with DD experienced major disruptions in the services and support they received.[5-7] Residential services, similar to other congregate care settings, had to find ways to operate safely. Community based day programs, clinical and other support services were forced to close or significantly alter the way they operated. The changes had large effects on the health and well-being of agency staff, the people living with DD, and their families.

In March 2020, the Toronto Developmental Services Alliance in Toronto responded to the COVID-19 pandemic by creating the Sector Pandemic Planning Initiative (SPPI). The SPPI is made up of staff from 28 agencies that provide services to people living with DD in Toronto, as well as Professor James Sikkema of McMaster University and Cheryl Wiles Pooran and Brendon Pooran of PooranLaw. Given the focus of the SPPI was mostly on higher level operational issues and needs, most of the agency staff that participated were in management. The SPPI is comprised of an overall Steering Committee and 4 working groups, Governance, Communications, Outbreak

The MARCO Programs

The Marginalization and COVID-19 (MARCO) study was started in spring 2020 by academic investigators, community investigators, and partner organizations working directly with people experiencing marginalization. Community investigators included people with lived experiences of marginalization, staff or leaders of community agencies, and people from advocacy organizations. We hosted a publicly available online survey to identify programs for evaluation. We considered a broad range of programs, interventions, and policies; these were not restricted to programs from MARCO partner organizations. A sub-committee of community and academic investigators selected programs based on: the potential for the research findings to have an impact on people experiencing marginalization; the need for the evaluation, relating to the current well-being of the population being served by the program; and the feasibility of completing the evaluation within available time and resources.

The MARCO programs are:

- COVID-19 Isolation and Recovery Sites for people experiencing homelessness
- Substance Use Services at a COVID-19 Isolation and Recovery Site
- Evaluation of Outreach Supports for People Experiencing Homelessness in Toronto Encampments During COVID-19
- Toronto Developmental Service Alliance's Sector Pandemic Planning Initiative
- Adapting the Violence Against Women Systems Response to the COVID-19

Problem Statement & Context

Problem:

- The developmental services sector was not fully prepared for the COVID-19 pandemic. Many agencies did not have pandemic plans.
- The pandemic caused major disruptions in service. Necessary guidance, procedures and supplies for matters related to Infection, Prevention and Control were not readily available.

Context:

- Evolving policies at the local, provincial, and federal level that do not necessarily account for need of developmental services sector
- People with DD and DS sector workers have vulnerabilities that intersect with other marginalized groups

Response:

- In response to the challenges brought on by the pandemic the Toronto Developmental Services Alliance (TDSA) formed the Spector Pandemic Planning Initiative (SPPI) to provide TDSA member agencies with information, resources and guidance to maintain safe operation of services during the pandemic.

Inputs and Components

Management and Staff from Developmental Service Agencies in Toronto with experience and expertise in:

- Organizational Management and leadership
- Human resources
- IPAC
- Client Service
- Research
- Project management
- Legal and Ethics

Steering Committee, Project Management Office (PMO) and 4 Working groups:

- Governance
- Communications
- Outbreak Management
- Research and Education

Activities and Outputs

- Regular Committee, PMO and Working Group meetings
- Identification of agency, staff, client and family needs through discussions and formal needs assessments
- Development of guidelines, recommendations, policies and resources to address safety, labour, legal, ethical and client service issues arising from the COVID-19 pandemic
- Dissemination of outputs through 1) email to DS agencies in Toronto and provincially, 2) meetings at regional multi-agency tables and 3) posting on REAL Xchange website https://realxchange.communitylivingessex.org/

Assumptions

- Agencies were receptive to the SPPI outputs
- Agencies attempted to implement changes based on SPPI outputs
- Agencies and staff have the resources (e.g. staff, skill sets, funding PPE) to adopt best practice-based support
- Agencies and staff are actively adhering and adopting infection control measures
- Staff and client well-being are connected

Outcomes

Organizational Short-term outcomes

- Organizations have increased information and knowledge to address safety, labour, legal, ethical and client service issues arising from the pandemic e.g.
  - COVID testing and clearance
  - Outbreak management
  - Re-opening
  - Work refusal and limitations
  - Essential visitors
  - Tools and resources for client support

Organizational Medium-term outcomes

- Alignment of organization's internal structure and roles/responsibilities for employer, supervisor, work er/staff with respect to new policies and procedures, e.g. Staff disclosures to leadership of personal information while maximizing privacy, implementation of health and safety guidelines etc.

Staff outcomes

- ↑ in staff knowledge of disease management and prevention measures (IPAC)
- ↑staff ability to perform their job functions safely
- ↓negative impact of pandemic on staff health and well-being
- ↑staff ability to support client health and well-being during the pandemic

People with developmental disabilities outcomes

- Enhanced well-being of people with developmental disabilities and their families during the pandemic
- Reduced infection and quick treatment
- Increased safety

Positive Impact on Families

Increased level of trust in agencies during COVID

Anticipated Long-term Outcomes

- ↑ pandemic preparedness
- Development and strengthening of relationships with other Non-DS partners – e.g. Public Health
- Development of new practices/contributions to best practice/long-term practice change e.g. adopting IPAC into staff training)
- Organizations have increased capacity to respond to future pandemic/health crises from policy and planning perspective

Figure 1. Logic model of the Sector Pandemic Planning Initiative

Management, Research and Education plus a Project Management Team that coordinated activities and initiatives. The overall purpose of the SPPI is to address safety, labour, policy, legal, ethical and service delivery issues as well as training and support needs, in developmental services arising from the pandemic. The SPPI developed a variety of information and position documents, tools and training resources that were distributed widely. The outputs were intended to be used by agency management, staff, adults experiencing developmental disabilities and their families to mitigate the negative impacts of the pandemic.

The purpose of this project was to evaluate the SPPI. To guide the evaluation a logic model of the program was developed with input from members of the SPPI. A logic model is a visual representation of a program's goals and outcomes. It outlines and connects the various components, outputs and intended outcomes. The SPPI logic model is shown in Figure 1.

Based on the logic model four broad evaluation questions were addressed.

- How were DS agencies, staff and clients impacted by the pandemic?
- How are DS staff and adults with DD marginalized and were they further marginalized during the pandemic?
- How did DS agency pandemic preparedness and response change over the course of the pandemic?
- Was the SPPI helpful in supporting agencies during the pandemic and if so, how?

A Community-Based Study

MARCO included community-based investigators, many with lived experience, as full partners. The MARCO Community Committee has representatives from 11 community agencies, representing a broad spectrum of organizations. MARCO's steering committee includes both academic and community-based investigators. Each program evaluation team included at least 1 community investigator and hired people with lived experience as peer researchers. Across MARCO, researchers with lived experiences of marginalization were involved in all aspects of the study, from recruitment and interviewing to data coding and interpretation.

TDSA

The Toronto Developmental Services Alliance is a network of 27 agencies that provide various services and programming for individuals living with developmental disabilities and their families. Through its member agencies, the TDSA advocates and addresses common issues for people with developmental disabilities and their families by developing and sharing best practices and addressing emerging needs. Read more https://tdsa.ca

Developmental Services

Developmental Services refer to services that provide support to adults living with Developmental Disabilities. In Ontario these services include community based programs, day programs and residential services. Developmental Services are often funded by the Ministry of Children, Community and Social Services (MCCS). People access these services through Developmental Services Ontario (DSO). There are 9 regional DSO organizations in Ontario that serve to determine service eligibility, assess needs and make referrals to appropriate services.

Methods

This evaluation received ethics approval from the St. Michael's Hospital Research Ethics Board. Participants were informed of the study and their consent to participate was obtained prior to data collection. An online survey followed by semi-structured interviews were used to collect data. Two versions of the survey were developed, one for management and another for direct support and clinical staff such as developmental service workers, case managers, case coordinators and allied health clinicians. Both surveys asked background questions about the respondent and the agency they worked for, pandemic preparedness before and during the pandemic, and infection prevention and control policies and procedures. The management survey also asked questions specifically about the SPPI. These questions were not included in the direct support survey staff since they were less likely to have participated in the SPPI and be aware of details about its purpose and activities.

Web links to both surveys were sent to executive directors from all 28 agencies participating in the SPPI, with the request that they distribute these within their organization. Responses were received between April and June 2021.

Following the survey, 4 agencies participating in the SPPI were recruited to be studied in more detail through interviews with staff. Attempts were made to recruit a mix of residential and day service providers, and large and small agencies. Like the survey, two separate interviews were created, one for managers and another for direct support staff. Participants were asked questions that describe their agency and their roles, agency pandemic preparedness before and after the pandemic started, the impact of the pandemic on operations, staff and clients, how the agency responded, vaccine roll-out, and issues of marginalization in the DS sector. Participants who were managers, were also asked about the SPPI, what resources were used, how they were used and how useful they were. Executive directors and other senior staff from the 4 agencies suggested people to contact to participate in the interviews. Our Research Coordinator reached out to suggested individuals and booked interviews with those who agreed. Interviews were conducted by either a Peer Researcher, who was a front line worker in a Developmental Services agency, or the Research Coordinator. Interviews were audio recorded and then transcribed using an online software called Trint. Using qualitative analysis, interviews were coded and organized into themes to address the evaluation questions.

Results

Survey Findings

Respondent Characteristics

53 people responded to the direct support/clinical staff survey. 47 indicated they were direct support workers, case managers or case coordinators and 6 indicated they were clinical staff (e.g. behaviour therapists, psychologists etc). 35 people responded to the management survey, 12 were vice presidents, CEOs, or executive directors, 4 were directors, 13 were managers, and 6 were supervisors. See Table 1 for complete sample demographics. The majority of respondents were women, heterosexual, White, and born in Canada.

Agency Characteristics

Table 2 presents information on the clients supported by the respondents' agencies and the types of programs provided. Participants worked for agencies serving a wide range of clients. Residential, day programs, and clinical supports were the most common service types indicated. 77% of management reported their workplace was unionized.

Pandemic Preparedness

54% of management respondents indicated their agency had a pandemic plan before March 2020, while 29% indicted their agency did not, and 17% did not know (Table 3). 46% reported their agency knew about the

Table 1. Characteristics of Study Participants

Characteristic	Staff (N=53)	Management (N=35)
Age		
20-39	22 (42%)	7 (20%)
40-54	17 (32%)	7 (20%)
55-69	6 (11%)	9 (26%)
Prefer not to answer/missing	8 (15%)	12 (34%)
Development Sector Experience		
1-10 years	24 (45%)	10 (29%)
11-20 years	18 (34%)	9 (26%)
21-30 years	6 (11%)	8 (23%)
31-40 years	2 (4%)	5 (14%)
41-50 years	0 (0%)	1 (3%)
Prefer not to answer	3 (6%)	2 (6%)
Gender Identity		
Man	11 (21%)	8 (23%)
Woman	40 (76%)	22 (63%)
Non-binary/gender non-	0 (0%)	1 (3%)
Prefer not to answer/missing	2 (4%)	4 (11%)
Sexual Identity		
Gay/lesbian/homosexual	2 (4%)	1 (3%)
Queer	2 (4%)	1 (3%)
Straight/heterosexual	42 (79%)	28 (80%)
Prefer not to answer/missing	7 (13%)	3 (8%)
Born in Canada		
Yes	36 (68%)	23 (66%)
No	14 (26%)	7 (20%)
Prefer not to answer/missing	3 (6%)	5 (14%)
Race / Ethnicity		
Black	7 (26%)	1 (3%)
East/Southeast Asian	4 (8%)	1 (3%)
South Asian	4 (8%)	5 (14%)
White	33 (63%)	2 (63%)
More than 1	2 (4%)	0 (0%)
Prefer not to answer/missing	3 (6%)	6 (16%)

Table 2. Agency Characteristics

Agency Characteristic	Staff (N=53)	Management (N=35)
People supported		
People experiencing poverty	31 (59%)	17 (49%)
People experiencing homelessness	29 (55%)	11 (31%)
People experiencing precarious housing	29 (55%)	16 (46%)
People who use alcohol	28 (53%)	13 (37%)
People who use drugs	28 (53%)	15 (43%)
People recently or still incarcerated	27 (51%)	11 (31%)
People at risk of survivor of IPV	27 (51%)	11 (31%)
Children or youth in unstable homes	26 (49%)	6 (17%)
Immigrants	25 (47%)	10 (29%)
Refugees	24 (45%)	7 (20%)
People who are Indigenous	24 (45%)	7 (20%)
People who identify as LBGTQ2S+	21 (40%)	15 (43%)
People with traumatic brain injury	21 (40%)	11 (31%)
Racialized communities	20 (38%)	13 (37%)
Don't know	10 (19%)	2 (6%)
Other	1 (2%)	4 (11%)
Age of clients		
Under 18	28 (53%)	14 (40%)
19-30	48 (91%)	32 (91%)
31-54	46 (87%)	34 (97%)
>55	43 (81%)	31 (89%)
People with high medical complexity	42 (79%)	19 (54%)
People with co-occurring mental illness	41 (77%)	23 (66%)
People with Downs syndrome	44 (83%)	23 (66%)
People with autism	47 (89%)	27 (77%)
People with fetal alcohol spectrum disorder	39 (74)	17 (49%)
Other	10 (19%)	7 (20%)
Do not know	1 (3%)	
Programs offered		
Residential	21 (40%)	
Day program	16 (30%)	
Clinical services and support	14 (26%)	
Case management/service co-ordination	9 (17%)	
Respite	8 (15%)	
Adult protection service workers	7 (13%)	
Education	4 (8%)	
DSO	2 (4%)	
Other	1 (2%)	

"[A] lot of [clients] are experiencing extreme isolation because they are at home. And this was sort of their place to meet with their friends and to be in a group. So that's a big thing."

Table 3 Pandemic Preparedness (Good/Very good rating)

	Staff (N=53)	Management (N=35)
Pre pandemic	24 (45%)	13 (37%)
Wave 1	38 (72%)	24 (69%)
Wave 2	48 (91%)	33 (94%)
Wave 3	47 (89%)	34 (97%)

recommendations that came out of the SARS commissions, 20% indicated their agency was not aware of these and 34% did not know. The percentage of staff and management respondents reporting that their agency pandemic preparedness was good or very good increased with each successive wave, with the exception of staff ratings from wave 2 to 3, which decreased slightly but was still very high going from 91% to 89%.

Impact of Pandemic

63% of management respondents reported their agency had had an outbreak. 80% of management indicated that staff had taken leave from their agency as a result of the pandemic. The various reasons for leave are shown in Table 4.

Pandemic Response

Staff ratings on use of PPE pre and post pandemic are shown in Table 5. While all types of PPE use increased, this was most marked for the use of masks. On a checklist question, management respondents indicated some of the ways their agency supported staff such as an EAP (40%), wellness initiatives (51%), mental health benefits and supports, and pay enhancements apart from benefits provided by government (29%) (Table 6). Other benefits listed by respondents in an open-ended question included gifts, taxi fare to and from work, hotel accommodation, opportunities to socialize on-line, a program to get staff vaccinated quickly, and equipment to support working from home.

Table 4 Reasons for leaves of absence

	Staff (N=53)	Management (N=35)
Immunocompromised	3 (6%)	11 (31%)
Live with people who are immunocompromised	3 (6%)	10 (29%)
Afraid they might be exposed to COVID-19 when travelling to work	4 (8%)	14 (40%)
Caring for sick family/friend	3 (6%)	12 (34%)
Increased child care	3 (6%)	14 (40%)
Experience high anxiety/stress	4 (8%)	19 (54%)
Worked as direct staff at another agency	0 (0%)	23 (66%)
Didn't want frequent testing	0 (0%)	1 (3%)
Didn't want to wear PPE	0 (0%)	4 (11%)
Didn't want expanded role	0 (0%)	1 (3%)
Other	0 (0%)	1 (3%)
Don't know	10 (19%)	6 (17%)

"And we're talking about people who can't go to mass vaccination clinics, who can't stand in line… So there is huge inequities not only for our population, but within our population."

Table 5: PPE use pre and post March 2020 - staff

	Never/ Almost never	Sometimes	Almost/ Every time
Gloves			
Pre	12 (25%)	19 (40%)	17 (35%)
Post	4 (9%)	12 (26%)	30 (65%)
Masks			
Pre	35 (76%)	6 (13%)	5 (11%)
Post	4 (8%)	2 (4%)	44 (88%)
Respirators			
Pre	40 (91%)	4 (9%)	0 (%)
Post	24 (60%)	7 (18%)	9 (23%)
Face shields			
Pre	38 (86%)	3 (7%)	3 (7%)
Post	8 (18%)	7 (16%)	29 (66%)
Googles			
Pre	37 (84%)	4 (9%)	3 (7%)
Post	12 (30%)	8 (20%)	20 (50%)

Table 6: Supports provided since March 2020

Support	Management (N=35)
EAP	14 (40%)
Flexible hours	5 (14%)
Wellness	18 (51%)
Mental health benefits and supports	12 (34%)
IPAC	9 (26%)
Pay Enhancement	10 (29%)
Other	19 (54%)

Was the SPPI helpful?

77% of management reported the SSPI was helpful (51%) or very helpful (26%). The resources endorsed as helpful in a checklist question are shown in Table 7. Other resources specified in a qualitative question included, documents related to re-opening guidelines and practices, social stories, IPAC, information on legal issues, and sessions on vaccines.

Table 7: SPPI Helpfulness

	Management (N=35)
How helpful was SSPI output?	
Very unhelpful	0 (0%)
Unhelpful	0 (0%)
Neutral	4 (11%)
Helpful	9 (26%)
Very helpful	18 (51%)
Don't know/missing	4 (12%)
Which SPPI was most helpful?	
Information	7 (20%)
Resources	6 (17%)
Products	1 (3%)
Policies	2 (6%)
Guidelines	4 (11%)
Other	13 (37%)
Missing	2 (6%)

Qualitative Interview Findings

24 qualitative interviews were conducted between June and October 2021, among 4 different DS agencies. We interviewed 10 direct staff (i.e. employment counsellors, community integration facilitators) and 14 management staff (i.e. executive directors, team leaders, program leads, and human resources). In the description of the results below, we have divided these roles into either direct support staff, management staff and executive staff.

The results are described in terms of:

- Impacts of the pandemic on service, staff and adults with developmental disabilities
- Marginalization experienced by clients and staff prior to and during the pandemic
- Policies, procedures and supports that agencies put in place to support service operations, staff and clients
- Facilitators and barriers to implementation and success of pandemic response
- Contributions of the SPPI to pandemic response

Impacts on service delivery, clients & staff

Impact on Service Delivery

The recognition of the COVID-19 pandemic and the resulting prevention measures put into place had a significant impact on the DS sector and its programs.

Residential programs continued to operate but had to modify operations substantially. Approximately one month into the pandemic, staff were limited to a single place of work, as opposed to holding jobs at multiple organizations, which was common practice before the pandemic. Agencies were also faced with the need to implement Infection Prevention and Control (IPAC) and public health measures, requiring social distancing and the use of appropriate personal protective equipment (PPE). In addition, non-essential visiting (in many cases the resident's family members) was stopped, although eventually returned with public health restrictions in place.

Initially, almost all day program activities, such as client employment, social and recreational activities, stopped. Many transitioned to virtual programming, but clients and staff experienced an array of challenges such as confusion and uncertainty, during this shift.

> "So initially, obviously, we just shut down completely and we're grappling with how are we going to do this? Because we all thought in March it would only be a couple of weeks, never knowing that 15 months later we'd still be here…We started providing virtual classes through Zoom for people who could, and so we did that." [Executive Staff].

> "Everything changed. I mean, realistically, the staff would normally go into the community, take the clients into the community. That was one of the hardest things. The clients have been literally in their homes now for a year and a half, not really engaging in the community, which has been very difficult for them. The staff also would be responsible for grocery shopping, taking the clients to get their medical appointments. All of that changed. Everything became virtual." [Management Staff]

> "Virtually like, can we do this online? Who's going to be in charge of what and how to best support the individuals and those that didn't necessarily have the technology? How can we still support them as well?" [Management Staff]

Another factor that influenced program closure was the location of programming as some programs were not held in the agency's premises and instead located in other organizations, such as the City of Toronto. Activities and programs housed in other organizational spaces were subject to further restrictions. Some of the day programs re-opened to in-person for a short period of time between wave 1 and 2 of the pandemic but closed again when cases increased and public health measures were re-instituted.

"At the beginning of last year when our house was hit with COVID, it was really a burn out situation, just really difficult"

Impacts on Clients

Interview participants identified a range of negative impacts that these changes had on clients.

Clients faced immediate disruptions in their routines including shifting to virtual programming, loss of activity, and contact with the community. Clients residing in residential homes lost regular visits from their family and friends. Some were able to remain connected with friends through other means while others could not supplement in person connections. Staff described how the circumstances resulted in isolation and stress for clients.

> "So I think a big part of his routine was thrown off. Right. So for individuals specifically, the program were put to a halt like there wasn't much. Like it was almost like the world turned upside down. The guys that were used to going home every single weekend are now not going home every single weekend." [Management Staff]

> "Well, a lot of [clients] are experiencing extreme isolation because they are at home. And this was sort of their place to meet with their friends and to be in a group. So that's a big thing. A lot of the people I support have been experiencing great anxiety about going out and doing things that they used to enjoy doing, even if they are safe, like going for a walk. That's [*too*] much for them even at this point. So that's a lot." [Direct Support Staff, Day Program]

The sudden changes were accompanied by a variety of behavioural changes and mental health issues among clients. Staff reported that some became reclusive, scared, angry, and were losing life skills they had previously gained. As clients encountered more stress, anxiety and depression also increased.

> "Because one of the things that we certainly saw was isolation. The isolation had a great impact on the clients and depression, you know." [Management Staff]

The switch to online services limited ability of clients to access or participate in non-residential service. When these programs initially transitioned online, some clients did not have devices to access virtual programming. Among those with adequate devices and technology, several still had challenges accessing programming online. Some managed well with this transition while others were disengaged and no longer participated in programming. For example, clients had lower attention spans on Zoom and felt overwhelmed with the number of people attending the video call.

> "As far as participants, some participants we have not seen in 15 months. They don't have

Passport Program

The Passport Program, funded by the Ministry of Children, Community and Social Services (MCCSS), helps adults with a developmental disability be involved in their communities and live as independently as possible by providing funding for community participation services and supports, activities of daily living and person -directed planning. The program also provides funding for caregiver respite services and supports for primary caregivers of an adult with a developmental disability. https://www.dsontario.ca/passport-program

the ability to be online. They don't have the resources. They don't have support at home. That's a huge one." [Executive Staff]

"About half of the people that I'm working with are having some sort of barrier to accessing the program. So whether that be they don't have a device that's working because they weren't able to acquire one or it broke or they have something, but they don't know how to use it and they don't have support at home. There's a few people whose parents don't know how to use the devices. So that's been a barrier." [Direct Support Staff, Day Program]

Families began to struggle to support adult children living at home who attended day programs that were canceled. These families needed alternate and additional supports throughout the day for their loved ones. While many of these clients had *Passport funds* (see page 19), the switch to using that money to support clients requiring significant care at home was challenging because the funds were insufficient.

"Money has been a huge barrier because all of a sudden people who have five days of funded support in the community still have that five days of funded support, but they're at home. Parents or caregivers or people who are supporters might have to go to work or not be able to be there and families don't have the money — their funding wasn't really increased to close that gap. So, I'm seeing a lot of families who have had to hire a support worker five days a week and they're paying out of pocket because their *passport* won't cover it, because they're in a five day funded program … Funding is always a thing, right, and thankfully, *passport* changed their list of items that [*you*] can purchase with that money and I think that list should have always been that way." (Direct Support Staff).

Public health measures also impacted clients. For those residing in residential settings, some clients found it difficult to understand social distancing measures and the importance of using PPE. Staff explained that these challenges were due to some clients having difficulty in understanding the pandemic overall.

"Especially in our sector, our individuals will come up to your face. They will you know, they might be affectionate. They might want to hold your hand as you're walking to their room and just ensuring that you're keeping your distance, because that could be hard for sure." [Management Staff]

Public health measures and restrictions further impacted medical appointments; some appointments were held virtually while some continued in-person. These restrictions also did not permit people to bring family members or other supports people to accompany them to their medical appointments and hospital visits, resulting in distress for those clients that continued with in person health services.

"How devastating it was that no staff were able to attend with individuals. It was devastating for our staff. It was devastating for individuals. We also have people who are non-verbal. And it just it was heartbreaking. It was absolutely heartbreaking to see them have to go through that and not have a voice and go to these strangers that don't understand them." [Management Staff]

In later stages of the pandemic some clients encountered challenges when attending their COVID-19 vaccine appointments. Although several agencies explained that clients were supported by mobile clinics, some clients were still required to travel to vaccination clinics. Many were not able to follow public health protocols while waiting in line due to the presence of a physical disability, challenges with wearing a mask for an extended period of time and following social distancing rules.

"And we're talking about people who can't go to mass vaccination clinics, who can't stand in line. They can't wear masks, not all ten thousand, but there are quite a few. And so then a whole other group had to advocate for that population. So there is huge inequities not

"Our sector was ignored. They are invisible. It took so much advocacy from leaders and organizations to try and make people understand…"

only for our population, but within our population." [Executive Staff]

Impacts of pandemic on staff

Staff also faced numerous challenges as a result of the pandemic. There was substantial job disruption. Requirements for staff to only work at one employer and discontinuing the use of temporary agency staff, led to staff shortages and redeployments. Impacts included changes in work location, such as day program staff moving to residential, and working longer shifts. In the early days of the pandemic, these problems were particularly acute and created challenges with staff in arranging schedules with their partners and family members and around child and elder care responsibilities. It was also challenging in some instances to take time off and to schedule vacation time. This was particularly problematic for new hires who never met their team in person and who worried about job security and the lack of sick days.

"As well as the staff who were working out of those programs. They've since been redeployed. Some of them are used to working on Monday to Friday, 9 to 5, and they have now taken on some by their own choice, 12 and a half hour shifts where they're doing a couple of days a week or they're working evenings and weekends, which is a little different from what they've had to do." [Management Staff, Day Program]

"Yeah, and walking in more than one agency, right? So with the one job restriction order that has impacted us financially." [Management Staff]

"I think my number one was, I would say job security, because I was in a contract position. I was covering someone else's mat leave. So in the beginning, it was it was tough because I was in I never met anyone in the staff. I met everyone through Zoom. So, like, when I say the first day I went to work, it was basically them announcing COVID, this is what COVID is, this is what's happening. And I was like, OK. And I went to work the next day and they were like, go home … I was kind of kind of taken aback because I didn't meet anyone. I had no idea what to do." [Direct Support Staff]

"But I also think that the reality was [the organization] were short staffed. I think a lot of staff maybe took leave or, you know, had kids out of school or they just they had like they had the need for more staff." [Direct Support Staff]

"I was new. And also I was working a different schedule too, than what I'm used to, because even though I was full time, I was put into basically whatever the staff that had gone on leave had. So I was working nights and I was working some overnights. And so that was very different for me too." [Direct Support Staff]

"The husband and wife thing, you mean, or the relatives working together? Yeah, I can hear you by your [screams]. Yeah, I mean, we worked it out with them. Opposite shifts or one of them took a leave" [Management Staff]

"I think at the time, we kind of did what we thought we could, but I definitely think there was room for improvement in terms of recognizing, you know, the burnout from stuff, you know, working 12 and a half hour shifts

with the exclusivity order that came in thereafter. We did lose some of our staff team. So, you know, them choosing another organization agency to be their primary source of income. [*It*] definitely impacted us." [Management Staff]

Along with shortages and scheduling challenges, when staff were deployed to residential settings, they noted this was not the work they signed up for. The work that staff had to do in the homes was physically tiring. Staff were exhausted with cleaning, wearing PPE and attending to client care.

"I think the first challenge was probably just being redeployed like that was on my team. Wasn't really the job I signed up to do. So it's just like I mean, I appreciated being in work in a time of uncertainty, no doubt. But at the same time, it was just like this, this isn't the job." [Direct Support Staff]

"At the beginning of last year when our house was hit with COVID, it was really a burn out situation, just really difficult, but I got through it and it was difficult in a way that when the government had brought when we had the emergency lockdown and the government had said we could only work for one employer or the part time people, we had gone to do full time jobs … And we are now working 12 hour shifts. And it was really difficult because the ladies were kept in their room. We have to support them in their room, like clean their room, have them take their food, their meds, their everything, all the dishes to their room and then pick them back up, then go back again, support them with their beverage. It was quite a challenge at that time." [Management Staff]

Similar to client experiences, some staff struggled with using technology. Some had major issues with setting up virtual activities and some found learning new technology to be draining. Most described feeling "Zoomed out" and had "Zoom burnout," and felt like they were "monitoring" clients, while working remotely online.

"Definitely burnout and drained from Zoom … it takes a lot of energy to entertain individuals on a computer and to keep the interest to stay around that computer. So especially during the main zoom, which is two hours and plus, one … eventually became exhausted." [Direct Support Staff]

"Sorry, I just want to mention that it is so exhausting to sit in front of a computer all day for the facilitators, but at the same time, it's also so not engaging for so many of the participants who communicate in different ways and interpret information in different ways." [Direct Support Staff]

"[Other staff] but here online, it felt like they were you were monitoring them. And it was much tougher because we were using the Teams platform where you're able to mute anyone or anyone was able to mute anyone and learning the technology it was a learning curve at first too, keeping making sure the participants are entering the correct room. And so all of those technological things got a little hectic for the staff. So it was it was more that aspect was more draining." [Direct Support Staff]

Non-residential staff were impacted by loss of contact with their clients. In some instances they did not know what was happening with their clients. They missed the human connection and many were further impacted by observing the behavioural and emotional challenges their clients were going through.

"My staff were burnt out, but it was for a very different reason. It wasn't for overworking, it wasn't for working 12 hour shifts, seven days a week. It was more about the missing people and trying to come up with engaging things for people virtually." [Executive Staff]

"Sure. So there were kind of, I would say, lots of cons, but some pros, so definitely we lost touch with some participants … So that was hard for staff. And we were stressed out about how people were negotiating this huge change to

"For residential programs, we established regular feedback sessions… We also certainly opened it up for their families to communicate. So I think we just really just got very intentional about communications"

their schedule. I think that was hard on the staff." [Management Staff]

These various impacts had effects on staff mental health. Staff noted mental health challenges, problems staying engaged and many noted burnout. There was also lack of knowledge about COVID-19, concerns about the vaccines and vaccination requirements and fear of getting infected and spreading it to their families.

> "At the beginning of last year when our house was hit with COVID, it was really a burn out situation, just really difficult." [Management Staff]

> "Yeah, except of course, mentally for us it's a little bit disturbed like too much work. And there's no life when you go home, you have to, scared what's going to happen, you know, we live with our family, so we really have to be cautious to maintain our distance. And like all of that, the protection we have to protect ourselves, we don't want to bring other diseases here that was really mentally affecting us." [Management Staff]

Marginalization

Our interview participants discussed how people living with DD experience marginalization, the impact of marginalization in both the DS work force and the overall DS system. Clients were described as experiencing marginalization based on living with a developmental disability and, as a result, experiencing stigma, isolation, health inequities, and poor access to healthcare, other services, and the COVID-19 vaccine. They were also described as belonging to other marginalized groups due to physical disabilities, mental health challenges, living in poverty and identifying as 2SLGBTQ+. The DS work force was described as being comprised of people who earn low wages, people who are racialized, and having a large proportion of single mothers. This intersectionality was seen as particularly true for staff who worked in residential settings.

> "I think many, many of our many of our staff are single mothers. I would say a good portion of our staff are black and many from the BIPOC area, including Indigenous, so I think it really became evident, particularly staff who were also supporting not only their children, but also an elderly parent. That became very apparent as it relates to poverty issues that we saw." [Executive Staff]

> "I mean, people with disabilities already experience huge amounts of social isolation and barriers to accessing things that they want and need. I mean, as we know, the current programs and resources that are offered for people with disabilities aren't really inclusive, right? Many programs, such as my program, it's a bunch of people with disabilities congregated together. So it is still very isolating." [Direct Support Staff]

Interviews illuminated how these pre-existing inequities and experiences of marginalization were exacerbated by the COVID-19 pandemic. Participants indicated that people living with DD, as well as staff and service providers who support them, are at a higher risk of experiencing a greater degree of negative impact as a result of the pandemic, compared to most others. People living with DD were experiencing even more isolation and staff were experiencing increased financial pressures. Both staff and clients are at a higher risk

of contracting COVID-19; the risk for people living with DD being heightened by poorer overall health and living in congregate settings, such as group homes. The risk for residential workers was heightened by working in congregate settings, having to travel by public transit and living with others who also have to commute because they could not work from home.

> "So once that piece of community was removed from them … they experienced more isolation than most other people do because they're already excluded from those other spaces and forms of community, right?" [Direct Support Staff]

> "And also, these people are high risk physically, too, for COVID, so that further isolate them because they're scared to go out." [Direct Support Staff]

> "We have to advocate more for better pay for our staff, because one of the biggest issues that we had was losing a lot of staff, because they have they can't make ends meet with just one job." [Management Staff, Day Program]

> "And then we see these reports that people with developmental disabilities were way more susceptible and way more likely to die and have severe reactions and even subsections within our population." [Executive Staff]

Interview participants made an important distinction between people with DD living in group homes versus those living in the community. Those living in the community were seen as facing a different set of challenges. For example, interviewees described financial difficulties faced by people who suddenly required full-time support due to the cancellation of day programs but not having the financial means to obtain such support.

> "But I think going forward, there has to be an understanding that the people who don't live in group homes, or they live with their families or even people who live on their own support are just as vulnerable and probably more vulnerable because they don't have the staff support with them all the time. And so they need they need a champion to kind of say, hey, these people need protection and they need plain language …. there has to be some kind of champion for those 10,000 people who live in Toronto who don't live in group homes." [Executive Staff]

> "So once they recognize that there are people living in congregate care settings, so then all the resources went to that and vaccinating staff and vaccinating residents and then the community people were ignored." [Executive Staff]

The DS sector was described as being ignored by the government. One participant described the importance of advocacy in ensuring the experiences of people living with developmental disabilities was recognized.

> "One hundred percent. Our sector was ignored. They are invisible. It took so much advocacy from leaders and organizations to try and make people understand that our participants were just as vulnerable as the people in long term care. But unfortunately, the population we work with has been long devalued, long devalued. So, you know, the fact that they were ignored was it was it was infuriating, but not surprising. And like I said, it took a ton of advocacy to get people to understand" [Executive Staff]

Agencies and the DS sector have responded to the various components of marginalization and the aforementioned challenges in several ways. For example, wage enhancements were provided and one interviewee indicated that residential workers at their agency were offered hotel rooms paid for by the agency with meal reimbursement to reduce the risk of spreading COVID-19 to their family members. In some agencies, committees were formed to address issues of discrimination and inequities in the work environment. Staff training focusing on equity and diversity was provided. Interviewees also spoke about policies and procedures to address situations involving discrimination in the workplace. Some agencies also have dedicated services and supports for

people with DD and their families who belong to other marginalized groups, such as new immigrants. Some interviewees indicated that while work was being done to address marginalization of clients and the workforce, progress was slow and more needs to be done.

Pandemic Response

Agencies responded to the pandemic with a variety of initiatives to support staff and clients. One staff described how the initial response to the beginning of the pandemic felt like organized chaos, however they remarked on the improvement, sense of community and confidence they feel now:

> "It was organized chaos like it just it was so chaotic and a lot of managing fear and a few of my locations experienced outbreaks. And, you know, we pulled together there … We did a great job. We had regular communications. The leadership team started off meeting daily in the mornings, went through any concerns, answered any questions we pulled on Toronto Public Health. We were involved … Now we just go through the motions. We've become experts at outbreaks and reporting to the Toronto Public Health and the ministry. And things have calmed a lot. There's not a lot of fear anymore. We manage that fear very, very well, I think, and we worked through it." [Management Staff]

The specific ways clients and staff were supported are outlined below.

Supports for clients

In light of the COVID-19 pandemic, service agencies, frontline staff and the overall DS sector, established many supports for clients attending both residential and day programs. Some supports were shared among both settings while others were specific to either service type.

Most day programming activities, if they continued, were offered virtually. Clients had mixed experiences with virtual programming as some were engaged and well connected whereas others experienced more challenges. Technical support was a critical component of establishing virtual programming and clients were offered iPads, tablets, as well as support in how to setup and use their new devices. Additionally, supporting documentation such as activity workbooks were also adapted to meet virtual programming needs and provided to clients.

> "And what the IT department had done, I'm just at the height of the pandemic, was to deploy tablets or iPads so that that communication could happen with the families." [Management Staff]

> "Well. Right now, I'm at my program site setting up iPads because we bought everybody iPads, which is fantastic. So that's going to help out a lot of people who don't have devices. So that's huge. And we're setting them up so that we know how they work. And so we know everything that they need is installed and everything [*is*] good to go. And then we can just show them how to use it." [Direct Support Staff]

Agencies also increased programming options. Agencies and staff recognized the importance of keeping clients engaged, connected and busy whether at their own home or in residential settings. Programs focused on being flexible to try to address various client's interests and needs and staff facilitated virtual activities such as dance, exercise, science experiments. Some residential settings provided access to cooking, baking, video calls, personalized Netflix subscriptions.

> "So we run a whole variety of different things. We've kind of adjusted it because we found that online it's very difficult to be fully engaging online all day. And I think we've kind of adjusted what we're offering based on the needs of our clients – because a lot of our clients have said, you know, I'm feeling stressed, I'm feeling frustrated, isolated, being at home. And so we have now some self-care programs, some meditation and things like that to help with that kind of thing. We do life skills as well. And then we have an employment program once a week, just talking about employment readiness. And then we also have a recreation facilitator that does like dance and

art and different things like that." [Direct Support Staff, Day Program]

Many agencies increased staffing and external resources to further support new programming initiatives and clients. For example, some agencies hired recreational therapists, massage therapist and behaviour supports.

"[*We*] beefed up the staffing to help just we tried to carry on as things were normal." [Management Staff]

When possible and permitted under public health guidelines, staff provided individual, one on one support to clients in the community by going for walks, sitting outside, and going to the beach. Occasionally, these activities included both clients and their caregivers or family members. These initiatives were integrated by agencies and staff in order to enhance socialization for clients and their families.

"So, again, when we could when we were allowed in public health, when there wasn't a lockdown, we tried to offer the participants some one on one support in the community for them as well as their caregivers, just to get them out for a walk, because we know that even just a walk can help your mental health or even a sit in the backyard. Like anything to get some fresh air and get them out of the four walls of their house." [Executive Staff]

In order to maintain a sense of connection with clients and families, agencies focused on increased communication. This included keeping families informed through webinars, weekly email announcements as well as offering direct email communication with agency executives or management. Residential settings scheduled regular resident meetings to communicate about health and safety protocols.

"For residential programs, we established regular feedback sessions, regular resident meetings, regular communiques that they didn't feel like putting a note in a box. They could do that confidentially and share any issues. We also certainly opened it up for their families to communicate. So I think we just really just got very intentional about communications. [Executive Staff]

To support clients, particularly those in residential settings, increased health supports were established. This included necessary health and safety supplies such as PPE, the creation of health teams with medical check-ins, medical care and help with understanding and receiving the COVID-19 vaccine.

"Well, we have the development of our health team. Who became more involved in specific cases with individuals with [redacted]. And staff teams were able to liaise with that in those situations, and it was also up to individual sites to ensure that individuals were engaged and [If] need be, they had access to their medical teams, [however] we could manage that. A lot of it was ensuring that medical appointments happen even if they were over the phone and still engaging with the residents." [Management Staff]

"It was constant checking in, showing them videos, lots of videos, getting vaccinated and why and try to use plain simple language social stories to communicate the importance of getting vaccinated." [Management Staff]

One participant recognized how previous trauma had impacted the clients and needed to be accounted for in the pandemic response.

"Now, what we found as well, particularly many of the people that we support, have really suffered a lot of trauma in their lives. And we know that the virtual support's — not that there's a lot of evidence in this area — that really are not as helpful. Right. So we try to look at ways by which to connect with individuals that would be respectful, even though we were not meeting with people in person. And so we did the best we could, but there were really some gaps." [Executive Staff]

Many staff noted that the use of social stories was particularly helpful in explaining information regarding COVID-19 infection, transmission, vaccination to clients and their families.

> "We created social stories to help the individuals understand what COVID was and how it's affecting people and lots of communication with the individuals to go." [Management Staff]

Agencies were also given access to increased sector funding as the Ministry of Children, Community and Social Services (MCCSS), established the COVID -19 Residential Relief Fund (CRRF) to provide organizations more access to computers and equipment. Additionally, the DS sector allowed more flexibility in moving funds across portfolios. These increases enhanced social and recreational programming support for clients. *Passport funding* provided to clients was also expanded to include digital equipment to supported clients with virtual programming and maintaining social connection.

> "But for those that were also on *Passport* funding, it was fantastic because they changed the requirements and had like a temporary eligibility list that definitely helps our individuals, our own *passport,* which is majority of them. So usually that goes towards community participation, go to the movies and sort of like sports events, live events. And we were able to pick up things like iPads." [Management Staff]

Supports for staff

In response to the COVID-19 pandemic, supports for staff were either newly established or enhanced across DS agencies. An extra emphasis was placed on health and wellness.

> "OK, the big one was the whole the health and well-being, you know, checking in with staff, making sure that emotionally we were stable, coming into work, feeling supported. So there were lots of pop up presentations on, we had the whole presentation agency wide on mental health." [Management Staff]

Financial support included wage increases from employers and government, benefits and supports, specifically related to COVID-19 exposure and infection. In addition, if staff were in need, in some instances there were pay advances. For those who did not qualify for the increased pay, some were allowed to work fewer hours.

> "I was very fortunate that my manager …. She also made sure that there were times where she knew because some staff were getting time and a half, not time and a half, but like the additional pay, they were front line. And because it was such a strict rule or category that you had to fall under, my role did not, even though I was on site … She said that I understand that we're at home and you have other responsibilities. I'm not able to pay you extra, but I can end your work time… earlier...And she told me going forward you can end early on Fridays." [Direct Support Staff]

There were various agency responses to scheduling and accommodations. Many agencies extended sick days to part time staff who were not previously eligible for sick days prior to the pandemic. In many cases, there was more flexibility for staff to take sick days; staff could use sick time due to COVID-19 exposure or if they wished to take a mental health day. Several staff noted that if they were to be diagnosed with COVID-19 they would be covered under WSIB. There were various responses to scheduling. Some staff noted that there were accommodations made to support family schedules (e.g. when both partners working) and child care needs. Some agencies elected to increase their full time employee roster and switched part time employees to full time status, which then provided them with benefits that they did not have access to before.

> "So if we suspect it or if some stuff came to us and said, you know, I think I've been exposed or whatever, then we sent them for testing or we sent them home. We were paying them, long before Doug Ford and his three days. If we made the decision that the staff can't be on site, we paid them and we did not take it from

their sick days. So we've been doing that. Staff that are off for longer than four weeks have to provide a negative COVID before returning. Yeah, every situation is different, but we've tried to support the staff as much as possible." [Management Staff]

"They encourage staff, if you have burnout, just take a day off. They are asking staff, how are you working especially for me my supervisor approach me that oh you know what you burn out why don't you take this weekend off or something, she telling me that. I have a staff to come for this time so don't worry just stay off [she] encouraged me to take a day off." [Management Staff]

"… each program did their best to ensure that there was support provided to their staff team. So, you know, looking at the schedule in terms of like child care and pickup and drop offs, I don't think there was anything uniformly done." [Management Staff]

"… but like I had a traumatic experience in between during work and my management team did say, you know what, you need to take the time off. You take it as much time you need off and you come back whenever you need to. You don't have to worry about it." [Direct Support Staff]

In addition to paid time for isolating, some agencies provided staff the option of staying in a hotel if they did not want to go home because of concerns about infecting family members and to reduce COVID-19 exposure via public transit. Other agencies provided taxi's for overnight employees to and from work, in order to reduce infection exposure.

"Well, it's first of all, recognizing that there was some people who couldn't - they wanted to work, but transportation was an issue. So at the height of COVID, when it say you're in a house where the staff and clients are positive, we would give the staff an option, because we want them to work, to stay in a hotel. So the staff would stay in a hotel, which would ultimately protect them, protect their families, and then they come to work. So we paid for that hotel for them close by to the agency, to whatever location that they were working. We provided the meals for them, whatever meals they purchase, those receipts were handed in and they were reimbursed for that." [Management Staff]

Supports for mental health and overall wellness were also prioritized. Staff shared how their agencies emphasized making use of the available EAP programs which were often extended to all staff, regardless of full time, part time or relief status. Many agencies arranged virtual trainings and sessions on burnout, mindfulness and self-care, yoga and meditation, more frequent check-ins and team building exercises.

"Our agency extended the EAP to everyone so kind of only applied to full time staff that were receiving benefits before COVID. And then when COVID started, they extended the employee assistance program to everyone, even if it were relief staff, part time, contract, so that they were able to. And then those benefits kind of increased like the counseling and supports increased in hours. There were certain amount of hours before, but then they increased it. So it was an unlimited amount of benefits that people could receive. There was also mental health and resilience training that was done within the teams, like all staff and our whole program and our whole agency, just to talk about what kind of things to look for. There also was a session added to talk about vicarious trauma and burnout." [Management Staff]

Organizations also demonstrated their appreciation of the staff and the work they were doing with online parties, gifts and giveaways, care packages, gift cards, helping with groceries and food drives. Surveys were done to obtain input from staff about what they wanted.

"And they would kind of do it all to have a survey to kind of say, like what? What are staff looking for? What are you guys looking for? And in order to, like, make you feel like, you know,

your mental health and your physical, like, well-being, or are they doing well during a pandemic." [Management Staff]

"What do you think about this thing that they did a great they did a good job because we get a coffee card and the lunch card and they give us even like a prize, something like that. So I spoke to my coworkers to see that they did a great job." [Management Staff].

The provision of technical support was also critical to supporting staff. This included providing staff with technology such as cell phones and laptops.

"They gave me this computer. So that's helpful. And a cell phone, which is great to work from home." [Direct Support Staff]

IPAC

IPAC was central to the response to the COVID-19 pandemic. Agencies implemented IPAC programs and practices. These included the use of PPE, social distancing, cleaning, disinfection and screening. Individuals stressed that these protocols were following Public Health direction.

"Well, I know there is the whole screening protocol that they've implemented, the whole IPAC support that we have in place. IPAC training, staff had to be trained and IPAC management and having team leaders identify this, IPAC representatives, leaders, and also the fact that we were able to connect with public health and initiate the vaccine process for staff and individuals and just maintaining communication in regards to what needs to be in the group home...and how to manage any outbreak management protocols. So, yes, we're ongoingly always in contact with what's going on, what needs to be done and implementations." [Management Staff].

"So, yes, virtually was a big step in that direction and making sure we were following proper protocols, ministry protocols, IPAC protocols. So we had to be, needed to be, meeting regularly weekly, twice per week, sometimes with issues and concerns, especially around handling COVID exposures, possible contamination, possibly, you know, catching COVID what we will do and just reiterating and reviewing those processes to make sure we, the individuals were safe and how we would best do the contact tracing, how we best were checking staff, screening staff, making sure we win when the time came for vaccination. Again, there was a lot of meetings in how we were going to handle it, how we were going to rule out the vaccine prospects for individuals." [Management Staff]

Training was a key component of the IPAC programs. IPAC training was usually undertaken virtually and one community organization was responsible for providing training to a number of agencies. The training was often reinforced or repeated at intervals. In addition to the virtual training, some teams went through scenarios at the workplace. Training was also repeated when the agencies were re-opening.

"And [training organization] go through like hazards, COVID, prevention, isolation, how to do isolation cleanup, how to do PPE, washing hands, managing infectious control, all those they went through all those …" [Direct Support Staff]

"We actually had to do quite a few extensive training and modules that we had to cover periodically within the guidelines. And yeah we had to do quite a few extra trainings online with like IPAC and some other facilities as well." [Direct Support Staff]

Interview participants also reported the accessibility, availability and use of PPE. Generally there were no issues with availability and some organizations went to some length to ensure workers had what was needed.

"That was actually very, it was it was very smooth. Like I, I remember I went to work and my management, my manager told me, hey, [name redacted], you're going to receive a box from head office with all the PPE and everything. And it came literally that day. So I

"Absolutely. [SPPI resources] were invaluable to our own tailored plan."

didn't have to wait around,,, When you get in, there is there's a big shield. There are masks provided. There was sanitizers, everything was always there. I don't think we ever fell short." [Direct Support Staff]

"We still get a good supply of adequate supplies of masks, gowns, shields, googles. Whatever we want, it is there and we still got the supplies, nothing has changed… " [Management Staff]

Problems with Pandemic Response

While the response from agencies was most seen as positive some challenges were identified. Some staff also indicated that the process for requesting sick leave was challenging.

"The actual process of taking a sick leave was worse on my mental health than just not doing it at all, to be honest. They put you through so much like you have to do a lot of paperwork and go to the doctor all the time and give up so much personal information and just constantly prove that you're sick. It didn't feel great." [Direct Support Staff]

In some cases there was mandatory mental health training and some staff expressed that these trainings eventually became repetitive and tiring. Staff also reported that at times, there was so much information being provided that it became confusing to follow.

Some also noted the burden of doing all the necessary IPAC procedures.

"It was a lot more work, basically getting everybody, all staffing on board. Social distancing, sending more sanitation to be done, wearing PPE properly, supporting the clients as well. During that time, well, everything was lockdown so they weren't going anywhere, however, in their own house, their space, how [*to*] supervise them, two persons on every level." [Management Staff]

Some did note challenges in using PPE.

"Most of the time I was on shift by myself, which was OK and kind of nice because I could have like the office space to myself when I needed a break from my PPE because I had to wear like a face shield. And, you know, all that cleaning gets kind of sweaty. Overall, it was a pretty good experience, but it got old pretty quickly being. By the end of the month, I was really happy to just go back to my position at home." [Direct Support Staff]

While some were provided with hotel accommodation if they needed to isolate others were not.

"I would have felt very scared because I wouldn't really be able to isolate myself anywhere because I live with other people. And I looked on the Toronto website for what to do for you have to isolate and you live with other people. And it said stay in a different room, stay in your extra bedroom that you have in your house and use a different bathroom. But I was like all of us live with other people, like, I don't have an extra bathroom. So I think, like when people were still very stressed at the beginning, that was one of the questions. If we contract COVID and we have to isolate, is [*agency name*] going to pay for us to stay somewhere so we can isolate? And the answer was no. I mean, people were like, well, what are we supposed to do then? We don't really have a choice to go

to this place or not and then when we're if we get sick, we don't have a place to safely isolate. And we have to put our families at risk. I don't know that that should have been [*agency name's*] responsibility, but I think it would have been helpful to know. Even the government was just like there's nothing you can do, so that was very frustrating. I think it would be it would have been helpful if we were given more resources or if they did a little bit more research to see if there's any supports out there for people in that situation. That would have been helpful. And even when I was deployed, I was like, OK, here's what's going to happen. worst case scenario, if I get sick or if I get exposed, I'm going to buy an air mattress and I'll sleep in the office, you know, like I don't know what else Because there's not really a way to isolate my house." [Direct Support Staff]

Facilitators to adjusting to the pandemic

A key facilitator to adjusting to the changing programming needs of the pandemic was having previous experience with digital programming.

"I think our staff in some programs were a little further ahead than others … So I would say because we had a footprint in digital programing as well as virtual programing on a lot of approaches in back in 2003, 2004 in establishing best practice programing and skill development and knowledge exchange for vulnerable populations. So we were supporting other agencies as well ourselves in scaling digital programs. And, in a couple of years leading up to the pandemic, we were also testing virtual delivery to look at how we [*could*] look at effective artificial reality programing approach, [*stickiness*] in learning. So we had some of the teams able to pivot extremely quickly to virtual programs and others not." [Executive Staff]

Some agencies successfully facilitated change by creating a team to manage pivoting to online and modified service delivery.

"So what we did was we established a dedicated committee … I can certainly share our plan because it had a number of domains that we worked across in terms of technology, in terms of programs, in terms of funding requirements, public health. So we established our domains and then established a representative staff committee and then started from the ground up involving the departments in their plan, giving them very directional approaches and how they would design their programs and adapt them and then overlaying it with an overall organizational plan that was shared with the board and funders and insurance companies and banks because they all seem to want to know how we were going to manage. And it really proved extremely helpful. And the committee was meeting at the beginning, weekly, biweekly, monthly." [Executive Staff]

Barriers to Adjusting to the pandemic

Initially, uncertainty about how long the pandemic would last delayed the transition to virtual programming for some agencies and was a barrier to adjusting to the pandemic.

"OK, so when the pandemic just started, I don't think anybody really had a sense of how long it would be or where we were going to be going. So I got redeployed and I was working in employment. So I was just working in a different, like field of [agency name], altogether for the first couple of months just because we didn't make a transition like a smooth transition to online. So I think programs just kind of took a halt for a little bit of time. And I was just working in a completely different department. And then we slowly got their selves together and figured out how to make our programs virtual and get the slides up and get Microsoft Teams running." [Direct Support Staff]

Another barrier to adjusting to the impacts of the pandemic was the evolving nature of the pandemic that led to multiple directives from government.

"Yeah, yeah. It was just really- at times that got very confusing. I found with IPAC particularly, I'm trying not to be critical here, but it just became you just got- I got 20 email a day some days. Like I'm trying to distinguish what was important, what applied to what area or sector." [Executive Staff]

While agencies were getting information from the Ministry of Health and local Public Health units they were also looking for guidance from the Ministry of Child, Community and Social Services. Some participants complained, however, that during the initial stages MCCSS was not as active as usual in providing direction/guidance to the sector.

"Challenges with government protocols versus the rest of the world … Getting validated information from the ministry, our ministry. So Ministry of Health, long term care, bam they're on it, they've got guidance, documents, et cetera. Our ministry, Ministry of Community, Children's Social services? Wow. Not helpful through all of this. Very slow to respond, very slow with guidance. So, yeah, it's been a big change. You're kind of like drowning and grabbing for a life preserver at the same time." [Management Staff]

"And getting direction has been a nightmare… the ministry has been incredibly negligent with day programs because they've given no direction … They're just leaving us kind of drowning to figure it out on their own, which is to me the most like considering that they require us to do all these things but for something this important, they haven't given us direction. It's just really, really frustrating. So we're kind of just doing it on our own within the safety measures that we know. And the big question is, what do I do with for me, my big question is eventually we won't be able to help for Zooms, what I do with unvaccinated staff. And then we also have some participants whose families have chosen not to get the vaccine. So what do I do?" [Executive Staff]

Directives came from a variety of government sources including public health (provincial and city) and different ministries. Because some agencies had multiple program types (residential and day programs), they often received different directives based on the type of program.

"Probably the biggest issue for us … as well as some of the early onset confusion on uncertain guidelines … So, it took some doing at the beginning just to really get clarity from the funder of Toronto Public Health as to what provisions were going to be applying across the many areas. But there were pretty good. Generally, they had they had some staff really go through some real anxiety issues, uncertainty, fear." [Executive Staff]

Contributions of the SPPI

Interviewees spoke positively about the information and resources provided by the SPPI, describing them as valuable in several ways, such as time saving, trustworthy, and helpful. The resources were shared by organizations with staff, clients and families.

"I believe they were I mean, we just constantly shared them, but not in a bombarding sort of way. We tried to organize it so that people would be able to sort through the inventory in the library and then allow the departments to work with their staff at various levels to start populating programs, peer to peer, that we're working. We didn't want to be dictating, you know, from head office, if you will. That's why we allow, really a multipronged approach for staff support." [Executive Staff]

"Education material was definitely used by the operational teams to share with their clients." [Management Staff]

Interviewees identified the following specific resources as being used within their agencies: social stories, opening up documents, single employer guidelines, and webinars.

"I think one of the social stories they did was about getting the vaccine. So I shared that with them because I think it was like in plain language. So I shared that with families in case

they needed it, because I'm not the one who takes people to get vaccinated. I shared it with the families and said, if this is useful, you know." [Executive Staff]

"And then the conversation started happening about limiting where staff would work, which sounded completely like no, like that goes against our ethos and all this stuff. Right. But we saw that it was happening in long term care homes. [*SPPI*] started putting documents out and then we changed our policy, too. And then the order came up from the ministry, [*which*] but we had already implemented that that protocol even before the ministry had had actually enacted that legislation. So it set us up for success in that way." [Human Resources]

Interviewees often stated that the SPPI resources were useful contributors to policy development. They often described processes in which SPPI resources were used in combination with other sources of information, such as Public Health, to develop policy in areas such as PPE procurement, IPAC and vaccination rollout.

"Absolutely. [SPPI resources] were invaluable to our own tailored plan." [Executive Staff]

"It was used to help inform and shape up planning for the future. And even now they set up something like a week or two ago, which is being scrutinized by our operational team as well." [Executive Staff]

"The resources helped shape our policies and our protocols. And they were used as a tool to shape [our] policies and protocols." [Management Staff]

In the broader context interviewees explained that it was useful to belong to a network because it made it easy to know what other organizations were doing and provided easy access to others you could turn to if you had questions.

"It's great to get the perspective of what other agencies are doing and then come to a formalized sort of one guidance document that we can all agree on and then put it out sector wide. It's extremely helpful." [Management Staff]

"And then also the networking, like I now have a whole group of other people that I can send an email to saying, hey, what are you guys doing about this?" [Management Staff]

Finally, interviewees stated that SPPI had impact beyond Developmental Services and was used as a model by the MCCSS for other sectors to follow.

"I brought that model into a regional planning model for youth justice, for violence against women. And I think what you saw was it set a gold standard for how work needed to be undertaken." [Executive Staff]

Discussion

What we learned

The SPPI can be described as a network. It is a system level, cooperative, response, by a group of agencies to mobilize resources and share information to address a wide range of issues in the DS Sector in Toronto that arose from the COVID-19 pandemic. In April 2020, the SPPI initially commissioned an online survey with 26 agencies (12 outside Toronto), to identify needs of DS staff, people with living with DD and those who support them, during the pandemic. The survey results and subsequent published report, helped shape the materials developed by the SPPI at later stages of the pandemic.[5] The results of our evaluation support the conclusion that the SPPI played an important role in helping agencies operate safely and address the needs of their staff and clients during the pandemic.

Initially most agencies were not prepared for the pandemic. The ensuing public health measures resulted in major disruptions to services for people with developmental disabilities. These disruptions led to variety of negative impacts on people living with developmental disabilities and the staff who support them. People living with DD experienced mental health challenges such as stress, anxiety, depression, anger, trauma, isolation, challenges with virtual programming, difficulty understanding public health measures, routine disruptions and loss of social supports.[6,7] At the beginning of the pandemic, their family members had limited resources and supports[8], and staff working in the sector encountered uncertainty, job disruption, challenges with accessing technology, burnout and fear.[5] These types of negative impacts are consistent with finding in other parts of Canada and the world.

The SPPI mobilized quickly to help agencies address a variety of challenges: such as the need for PPE; information and resources to guide policy in areas, such as IPAC; human resource/staffing; and the legal and ethical issues that arose in these areas. It also developed resources to help staff with direct client care duties and to support their own health and well-being.

The SPPI was not the only source of information to guide agencies. However, the agency leaders clearly indicated that its resources were used to help shape their organizational policy needs during the pandemic, in areas such as PPE procurement, single employer requirements, IPAC, vaccine roll-out, and re-opening. They also indicated that resources meant for staff were shared widely within their agency. Staff reported using specific resources such as social stories and attending SPPI webinars.

Interviews highlighted that the experiences of marginalization among people living with DD and the workforce supporting them was a major issue even before the pandemic. A number of pre-existing inequities were exacerbated by the pandemic[5,9] and were made even worse by sector staff feeling as though their needs and the population were being ignored. Marginalization and a variety of inequities experienced by these groups were described as exacerbating the negative effects of the pandemic. Compounding the problem was the perception that the DS Sector was ignored by government. Most notably, issues in the long-term care sector received a lot of media attention and an almost immediate response from government. The parallels between challenges in group homes and those in long-term care were evident to those working in DS early on in the

pandemic. Had these similarities been recognized by government earlier, some of the measures, such as single employer requirements and wage enhancement, may have been implemented sooner. It can also be argued that this sector-level marginalization made the forming of the SPPI even more important and necessary.

Perhaps contributing to the marginalization of the DS sector is that it resides in the Ministry of Children, Community and Social Services, whereas Public Health sits in the Ministry of Health. SPPI undertook early efforts to include Public Health in discussions and planning. Efforts had early success but, as the pandemic placed exceptional pressure on the system, this access ceased. Staff changes, constant redeployment of resources, little to no DD experience or expertise, and competing pressures also resulted in a lack of consistency and attention from Public Health. While there is good reason for DS to sit in a different Ministry, it speaks to the need for Public Health and public health agencies to recognize multiple populations and service sectors in pandemic response and not just those housed within the Ministry of Health or the Ministry of Long-term Care. This recognition may have prevented some of the impacts that arose directly out of marginalization for people with DD. For example, the recognition that many people with DD require support people for medical visits could have improved their access to healthcare at the beginning of the pandemic. To ensure improved DS supports from Public Health for any future community health crises, SPPI has committed to facilitating the undertaking of research and evaluation, to provide formal recommendations for Public Health.

Key facilitators to the success of the SPPI can be identified. One factor not addressed in the evaluation but evident in the existing context, is that this group of agencies already had a pre-existing working and cooperative relationship through the Toronto Developmental Services Alliance, through which they addressed sector issues. It is hard to imagine the agencies mobilizing so quickly to form the SPPI and cooperating so effectively to develop agency, staff and client supports without this longstanding relationship.

A second important contributor to the SPPI success was the effective communication of information and resources. Resource documents were posted by the SPPI on the Real Xchange website and distributed to specific individuals from agencies by email. There is strong evidence to support the subsequent sharing of this information within agencies. In a broader sense, the SPPI provided its members and their staff with easy access to reliable up-to-date information. The evolving nature of the pandemic and constant flow of information from multiple sources was cited as a barrier to adjusting to program and operation changes during the pandemic. The SPPI was viewed by interviewees as a trusted provider of relevant information that helped agencies to identify and focus on their important needs. This access would not have been possible without effective communication and sharing of information.

A final facilitator to agency level success in the pandemic response was experience with technology. Agencies that already had experience with virtual service were able to move their program on-line relatively quickly. While this was not necessarily dependent on the SPPI, technical capacity and readiness at the system level is essential. The SPPI and similar networks might address this issue in the future.[10, 11]

Recommendations

1. The SPPI was an effective approach to rapid pandemic responses and preparedness. We recommend other sectors working with communities who experience marginalization consider establishing similar networks with agency-based leadership, in partnership with public health. Networks can work on a variety of system issues including future pandemic preparedness and will prepare these sectors for future events of this magnitude.

2. Many agencies were not aware of the recommendations arising after the 2003 Severe Acute Respiratory Syndrome (SARS) outbreak. Agency networks should make pandemic and emergency preparedness an on-going area of concern so that information is preserved and up-to-date. The SPPI is actively putting together a pandemic preparedness field guide for agencies. This should be revisited on a regular basis, perhaps annually, after the pandemic and updated as needed to ensure the knowledge contained within is not lost or becomes obsolete.

3. Attention should be paid to developing and continually updating the capacity of all agencies to deliver virtual supports to clients both during the pandemic and once the pandemic is over. While agencies can make this a priority, assistance from government and other system level entities should also be a priority. Government could consider dedicated budget lines, training programs, system wide infrastructure and funding research and development. Agencies should consider continuing at least some on-line programming after the pandemic. To do so they will need to ensure their staff and clients have access to sufficient and reliable internet networks and connections. Both staff and clients will also require appropriate and effective technical training.

4. Public Health and government should recognize inequities and marginalized populations and factor these into pandemic preparedness and response. They should actively seek participation in system level committees from representatives of such sectors. Representation should come from people with lived experience and family members as well as agencies. As part of this strategy both government and Public Health should also seek out and recognize groups such as the SPPI who work on pandemic preparedness, and advocate for specific populations. At the same time, these sectors and their agency based networks should advocate to be active participants in sector level health and public health initiatives.

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Affiliations

Centre for Addiction and Mental Health: Yona Lunsky

Pegasus Toronto: Chelsea Conrad-Ferguson

Surrey Place: Barry Isaacs

Unity Health Toronto: Anna Durbin, Linn Holness, Uzma Ahmed, Rosane Nisenbaum, Kahiye Warsame, Ahmed Bayoumi, Michelle Firestone

University of Toronto: Ahmed Bayoumi, Anna Durbin, Michelle Firestone, Linn Holness, Peri Ren, Rosane Nisenbaum