RESPONDING TO THE COVID-19 PANDEMIC CHALLENGES FOR FAMILIES WITH CHILDREN IMPACTED BY NEURODEVELOPMENTAL DISORDERS

RESPONDING TO THE COVID-19 PANDEMIC CHALLENGES FOR FAMILIES WITH CHILDREN IMPACTED BY NEURODEVELOPMENTAL DISORDERS

A partnership with

Mitacs

Kids Brain Halth Network

ABLE2

Queen's University

January 2021

Primary author: Maude Champagne, PhD Candidate, Center for Neurosciences Studies, Queen's University, Kingston, ON

Second authors: James Reynolds, PhD., Chief Scientific Officer, Kids Brain Health Network; Rachel Willis, Undergraduate Research Student, Queen's University, Kingston, ON

ACKNOWLEDGEMENTS

The authors gratefully acknowledge that this collaboration was made possible with funding provided by Mitacs, Kids Brain Health Network, Queen's University and ABLE2. Maude Champagne was the recipient of a Mitacs Accelerate Internship Award. A special acknowledgement and thanks is extended to the participating families for sharing their stories with us and contributing to the improvement in services provided by ABLE2: Support for People with Disabilities (ABLE2) for families impacted by Neurodevelopmental Disorders (NDD).

ABBREVIATIONS AND TERMINOLOGY

ASD	Autism Spectrum Disorder
CP	Cerebral Palsy
FARP	Fetal Alcohol Resource Program
FASD	Fetal Alcohol Spectrum Disorder
ID	Intellectual Disabilities
NDD	Neurodevelopmental Disorder

TO CITE THIS REPORT

Champagne, M., Willis, R., and Reynolds, J.N. Responding to the COVID-19 pandemic challenges for families with children impacted by Neurodevelopmental Disorders, Queen's University, January 2021

CONTACT INFORMATION

Maude Champagne

20mc17@ queensu.ca

Dr. James Reynolds

jnr@queensu.ca

Heather Lacey

ABLE2

hlacey@able2.org

Table of Contents

ACKNOWLEDGEMENTS 2

ABBREVIATIONS AND TERMINOLOGY 3

TO CITE THIS REPORT 3

CONTACT INFORMATION 3

Executive Summary 6

BACKGROUND 7

OBJECTIVES 8

CONTEXT 8

CONSENT AND ETHICAL ISSUES 9

METHODS and RECRUITEMENT 10

ANALYSIS 10

RESULTS 11

PARTICIPANTS 12

Challenging Behaviours 16

Police Involvement 18

Attachment, trauma, and mental health 19

School closure 20

Caregiver Mental Health 21

No break from the child 22

Placement instability 23

GENERAL SATISFACTION 25

FAMILY SUPPORT 25

CAREGIVER SUPPORT GROUP 26

YOUTH SUPPORT GROUP 27

Specific recommendations for ABLE2 29

  Barriers to access 29

Aggression displayed by children towards family members 30

Systemic recommendations *30*

Respite 31

Mobile crisis unit 31

Mental Health Intervention 31

APPENDIX 1 : Verbal consent form *35*

APPENDIX 2: Consent form for qualitative interview *36*

APPENDIX 3: Qualitative interview questions *39*

APPENDIX 4 : Survey questions *41*

Executive Summary

ABLE2 is a community-based not-for-profit organization that provides support for people living with disabilities and their families in the Ottawa region. During the COVID-19 pandemic, ABLE2 offered three online programs to support families with children impacted by neurodevelopmental disabilities (NDD). Since the beginning of social distancing measures, there has been an increase in participation in online programs, and increased reports of caregiver burnout, social isolation and feelings of loneliness, mental health issues impacting all family members. ABLE2 identified a gap in knowledge regarding the experience of families accessing online supports and formed a partnership with the Kids Brain Health Network, Queen's University and Mitacs to conduct a research study to address this gap.

The main objective of this project was to gain better understanding of the social support needs of families with children with NDD during the pandemic and how to adapt established support services to these emerging needs. The specific aims of the study were to (1) identify the needs of caregivers during the pandemic, (2) make recommendations to modify and adapt ABLE2's services to best meet these needs, and (3) evaluate the accessibility to and satisfaction with: i) virtual training, ii) virtual support groups and iii) virtual family support services.

An online survey was used to capture information on (1) family situation regarding COVID-19 (depression, anxiety, family violence, placement disruption and other social issues); and (2) Virtual support group satisfaction. Semi-structured interviews were used to explore the needs and challenges of families during the pandemic and client satisfaction with virtual services. Interview transcripts were coded and analyzed with NVivo analysis software using Interpretative Phenomenological Analysis (IPA).

All the families that volunteered to take part in the qualitative interviews are raising one or more children with Fetal Alcohol Spectrum Disorder (FASD). The most significant finding for children was an increased incidence of challenging behaviours, including aggression towards other family member. Previous mental health issues have been exacerbated in these children due to the disruption in services and regular routines and structures (such as school) and increased social isolation. Caregivers reported regression in children related to anxiety about their situation, and some previous trauma behaviours resurfaced. Some youth do not identify with the FASD diagnosis, or were too young for virtual services, and therefore did not participate in the youth support group.

Challenging and dangerous behaviours exhibited by children severely impacted the mental health of caregivers. Some caregivers reported experiencing Post-Traumatic Stress Disorder as a result of caring for their child. Placement instability was identified as a major concern by several families.

Recommendations for ABLE2:

- Smaller group size for caregiver support groups and a hybrid model between in-person and online services.
- Rename youth group for teenagers who do not identify with an FASD diagnosis.
- Phone calls to children too young for support groups if requested by the caregiver.
- Consider the barriers that biological mothers face in accessing FASD services.
- Respond to the pressing issue of aggression display by children towards caregivers and siblings.

Systemic Recommendations:

- Provide resources for FASD-informed respite options that are accessible and safe during the COVID-19 pandemic.
- Resume mobile crisis unit as an essential service.
- Enhanced support to address mental health needs of caregivers.

BACKGROUND

Neurodevelopmental Disorders (NDD) include brain-based disabilities such as Autism Spectrum Disorder (ASD), Cerebral Palsy (CP), Fetal Alcohol Spectrum Disorder (FASD), and Intellectual Disabilities (ID). Most studies on NDD do not include multiple types of disabilities but usually focus on a single diagnosis. For this research project, data collection and analyses were intended to reflect the common issues faced by a wide variety of ABLE2 clients. However, the majority of clients involved through ABLE2 programs who responded to the invitation to participate in this study are raising children and youth impacted by FASD. These children and youth are especially vulnerable, as they are at higher risk for mental health diagnosis [9]. Research on FASD shows that about 94% of this population experience mental health issues, which can be exacerbated during time of stress [9]. Disruptive behaviours such as aggression and tantrums are more common in FASD [12] and, when experienced on a regular basis, these behaviours affect all members of the family. The frequency and severity of these disruptive behaviours are directly related to mental health issues for caregivers and siblings, caregiver burn out, and even placement breakdown for those who joined their family through adoption [8, 13,14,15].

A large body of evidence has confirmed the reality of the intense stress placed upon these families during precarious times. A Canadian study sampling families raising children with FASD or ASD reported very high levels of stress in comparison to other samples [8]. These stressors impact the whole family in terms of financial, educational, emotional, and social needs. Caregivers face many challenges such as a lack of respite that often leads to physical and mental health problems [1,8].

Previous experience with pandemic responses has established that whilst these disruptive events lead to a general increase in rates of depression, anxiety, substance use, loneliness, domestic violence, and child abuse, marginalized populations are at much higher risk for these adverse outcomes [4]. Families raising children with NDD already face significant challenges, and many advocates and experts have warned of the additional negative impact COVID-19 is having on their quality of life [2,5].

The United Nations (UN) has recognized the vulnerability of individuals with disability while facing this unprecedented pandemic and has made policy recommendations for disability-inclusive responses to COVID-19 [4]. Including people with disability in the pandemic response is critical. The UN's recommendations include data gathering to ensure accessibility and adaptation of services in alignment with pressing needs identified by this population. As an organization, ABLE2 values the inclusion of people with disabilities by seeking their input to inform service delivery; this is accomplished through surveys, interviews, and membership on boards and committees. Surveys and qualitative interviews for caregivers were used to consult with families throughout this research study.

OBJECTIVES

The main objective of this project was to gain better understanding of the social support needs of families with NDD during the pandemic and how to adapt established support services to these emerging needs.

The specific aims of this study were to:

- ⇒ Assess the needs of caregivers during this crisis.
- ⇒ Make recommendations to adapt ABLE2's services to needs identified; and
- ⇒ Assess the accessibility and satisfaction of virtual support groups[1] and virtual family support services.

Expected outcomes of this initiative are the following:

- ⇒ Improve family dynamics.
- ⇒ Reduce stress of family members.
- ⇒ Improve developmental outcomes for children and youth with NDD.
- ⇒ Inform further policy with data gathered by this initiative.

CONTEXT

ABLE2 has three programs supporting families with children impacted by NDD; Walking in My Shoes, Sibling Group and Fetal Alcohol Resources Program. Since March 2020, the COVID-19 pandemic has brought many challenges to families already strained by the complexity of caregiving

---

[1] Support groups are caregiver support groups and the youth group.

for children with neurodevelopmental disabilities [1]. Since the beginning of social distancing measures, ABLE2 programs have modified service delivery to now offer virtual support to their clients (i.e., virtual youth and, family support groups and training). In this period, ABLE2 staff have noticed an increase in groups' attendance, caregiver burnout, social isolation and feelings of loneliness, mental health issues for all family members, and even increased violence in the home (through child-to-caregiver violence). In the hope to better respond to their clients' needs, ABLE2 aimed to assess the needs of caregivers during the public health crisis; in doing so, the organization was seeking to adapt service delivery to the needs of the community. The goal of this research study therefore was to determine the impact and effectiveness of virtual support groups and family support services during COVID-19.

CONSENT AND ETHICAL ISSUES

The protocols and procedures for this research study were reviewed and approved by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board which is in line with the Canadian Tri-Council Recommendations for Research with Human Participants. Survey results were anonymous. For the qualitative interviews, informed consent was obtained verbally using the verbal consent form (see Appendix 1). All participants were given a consent form ahead of time and had time to read the form and ask questions (see Appendix 2). Participants' confidentiality was protected at all times and they were identified using a number and pseudonyms. Audio recording of the qualitative interviews were destroyed after all transcripts were prepared and were transferred to a secure REDCap database at Queen's University. When planning for this research study, it was expected that the three programs serving children with NDD would be included in the process. However, Walking in My Shoes (WIMS) ended in June 2020, so this project was removed from the study. The Sibling Group is a monthly support groups for siblings of a child with a disability. A survey was sent twice to the program's clients but received only four responses.

METHODS and RECRUITEMENT

FARP[2] staff sent an invitation to complete the survey and to participate in a qualitative interview to their clients using an email invitation prepared by the intern; around 70 clients were contacted. Clients could follow the link to complete the survey anonymously and could participate in the interview by contacting the intern directly (see Appendix 3).

Semi-structured interviews were conducted by the intern and a neuroscience undergraduate student. The interviews lasted between 35 to 65 minutes and explored the needs and challenges of families impacted by FASD during the pandemic as well as client satisfaction with virtual services (see Appendix 4).

ANALYSIS

Survey results were gathered and analyzed using Qualtrics Software and transferred to Prism Software to performed graphs.

Interviews were recorded with the encrypted version of Zoom and transcribed by a professional transcriber. Transcripts were coded and analyzed with NVivo analysis software using Interpretative Phenomenological Analysis (IPA).

Transcripts were read mulitple times. Both coders indiviudaly coded the first three interviews and met to review the codes and amalgatmate them into main themes and sub-themes. Remaining interviews were coded and NVivo coding comparison showed high inter-rater reliability. Coding was done using Interpretative Phenomenological Analysis (IPA). This approach in qualitative studies aims at understanding the point of view of the participants and is concerned with understanding the meaning attach to their experience [10].

---

[2] **Since WIMS closed and the Sibling Group responses generated only four responses, data presented are only from the FARP program and focus on FASD.**

RESULTS

Figure 1: Word cloud of most common words

PARTICIPANTS

Ten participants responded to the invitation to take part in a qualitative interview. As seen in the table below, only one male caregiver responded to the invitation. The caregivers who participated in the study are all adoptive caregivers (two kinships). The age of these caregivers ranged from 40-69. The age range for children was 6-24, with a mean age of 14.

Table 1: Caregiver's demographic

Characteristics	Total Sample, (N = 10)
Caregiver Gender	
Male	1
Female	9
Other	0
Caregiver Age	
40-49	4
50-59	3
60-69	3
Years in a couple	
10-19	3
20-29	2
30+	2
NA	3
Nature of relationship	
Heterosexual	7
Homosexual	0
NA	3
Highest level of education completed	

Highschool	0
College/diploma	2
University/ degree	6
Professional/graduate school	2
Approximate family income	
$50,000 - $99,999	2
$100,000 - $149,999	1
$150,000 - $199,999	3
≥$200,000	1
Not specified	3
Living environment	
Urban	5
Rural	5
Total number of children	
1	2
2	6
≥3	2
Number of children receiving/have received support from an FASD worker	
1	7
2	2
3	1

Table 2: Children supported by the FASD Worker program demographic

Characteristics	Total Sample, (N = 14)
Caregiver/child relationship	
Adoptive	12
Kinship placement	2
Biological	0
Support from FASD worker	
Previously	2
Currently	12
FASD diagnosis	
Yes	6
Strongly Suspected	7
At risk	1
Child age	
5-9	3
10-14	3
15-19	7
20-25	1
Other mental health diagnosis	
ADHD	7
Anxiety	6
- Separation anxiety	2
Trauma	2
RAD	2
ODD	2

ASD	2
Other*	7

*Other mental health diagnosis include; intellectual disability (n=1), learning disability (n=1), depression (n=1), sleep disorder (n=1), sensory processing disorder (n=1), Disruptive Mood Dysregulation Disorder (n=1), developmental delay (n=1).

While only two caregivers reported in the demographic form that their child is diagnosed with attachment issues or trauma, the fact that all children were adopted speaks to the probability that most of these children have experienced disrupted attachment and/or trauma (25).

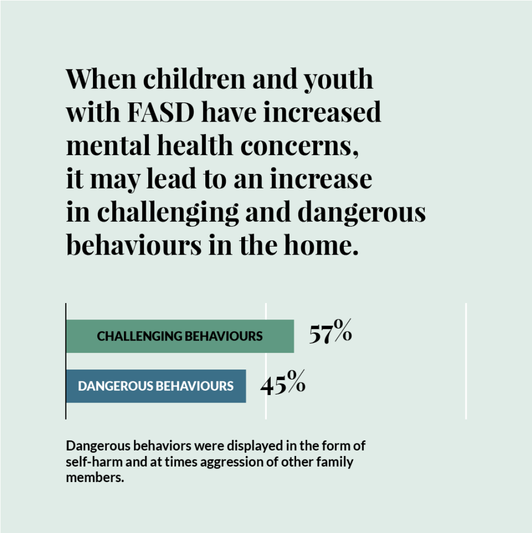
The survey generated 17 responses and was available in both English and French. All responses were answered in English. The 17 caregivers completed the survey for a total of 21 children. Children were between 6 and 20 years old (mean age=11.86).

The children

Challenging Behaviours

The main concern identified by all caregivers was in regard to their child's challenging behaviours (n=10) including child to caregiver aggression (n=8). Challenging behaviours refers to constant bothering, not following instructions, not sitting still when required, speaking loudly, etc. Dangerous behaviours refers to physical or verbal aggression that poses a threat to the safety of another individual or to themselves such as biting, kicking, name calling, destroying objects, hitting, self-harm and unsafe sexual behaviour. Families described these problematic behaviours at length, accounting for 1/3 of the coding references related to family members.

57% of caregivers reported an increase in dangerous behaviours since the beginning of the pandemic and **45%** of caregivers reported an increase in challenging behaviours since the beginning of the pandemic.



When children and youth with FASD have increased mental health concerns, it may lead to an increase in challenging and dangerous behaviours in the home.

Dangerous behaviors were displayed in the form of self-harm and at times aggression of other family members.

In interviews, families described the oppositional behaviours they face and the difficulty with the constant interruptions:

> His acting out behaviours became more apparent. A lot of just bugging, like just bugging, bugging, bugging, like when I would be on work calls and stuff, he would just, you know, come in and just bug, just to bug. And, so, and he became very needy. He became very obstinate. So, you'd ask him to do something and he would just, nope, I'm going to do this instead, or I'm not going to do it or whatever. (…)

Challenging behaviours are common for children with FASD and even during regular times, are a major source of family stress [8]. While two families reported coping fairly well, eight families reported experiencing child to caregiver violence and aggression. Dangerous behaviours were directed towards others in the form of violence and aggression or destruction of property.

> Andrew [3]had meltdowns where he's destroyed things and even hurt me.

> Well, our lives were at risk. I mean, there were times that Morgan attacked me with a knife. She knocked me in the head with a marble sculpture. Like she really…our lives have been at risk at times.

> We were dealing with child-on-caregiver aggression and violence and I just felt like I was a prisoner in my own home, you know, forced to live with my abuser because my abuser is my son, and so I just…I was so afraid and nervous all the time that, you know, basically the next hit or kick, or whatever, or something else getting broken, and so I desperately needed that break.

While some of the dangerous behaviours may pose threats to caregivers, these behaviours may be directed at themselves in the form of self-harm and inappropriate sexual behaviour:

> And the other thing with Christine is, the main reason why Christine… where everything broke down and stuff is Christine uses electronics inappropriately. Okay. So we've had the police involved quite a bit with Christine. And she does a lot of not very good things on the internet and on cameras and things like that.

---

[3] *Pseudonyms are used throughout the report.*

Dangerous behaviours also affect siblings who have at times themselves been adopted and are living with a Neurodevelopmental Disorder. One family in particular spoke about their son with FASD being really difficult with their daughter who is herself living with FASD. Three of the families had multiple children with FASD, two of which found increased tension between siblings.

Siblings were often described as neurotypical children having to cope with the challenges of having a sibling struggling with NDD. However, many adoptive homes have several children with a trauma history and FASD. The crisis many families found themselves in resulted in these children and youth re-experiencing trauma:

> He's really hard on her. He attacks her from the minute she gets up in the morning. It's really bizarre behaviours that we see. It's quite hateful. She is safer at work, better for her mental health to be out of the house.

> Zack's behaviours are almost always targeted to myself or Harry. It's not towards Kaitlyn, not physically, like he'll be at jackass to Kaitlyn but he's not physically abusive or aggressive towards her. It is very much targeted to Harry and I. Now, Harry is different. With Harry it's much more, you know, it's almost, it seems to go to like full sensory meltdown and he just lashes out at whoever's closest, you know, so he's hitting, kicking and it could be any of us.

Police Involvement

Police involvement was mentioned by three caregivers in the context of a justice issue involvement and having to deal with a mental health crisis. One caregiver reported having to call the police 2 to 3 times a week at times. Since Youth Service Bureau is no longer providing support in-homes to help caregivers deal with crises, police are often called even if it isn't always helpful:

> And that instability, she was a child in crisis over the COVID period. Incidents that would happen that required police intervention, happened frequently, like two to three times a week. And our family was not feeling safe and it was hard to keep her safe. So, she did well for the first say four or five weeks, and then we just plummeted. (…) I have to get through a violent episode by myself because I don't want to call the police, or I have to call the police and we end up spending the evening in CHEO. So we're losing, like, we've lost some valuable services that we need as in-person services (in reference to YSB in-home crisis support).

Attachment, trauma, and mental health

Caregivers expressed serious concerns over their child's wellbeing and their desire to provide a safe home amidst the troubles they are experiencing. All the children included in our sample have been adopted and have been prenatally exposed to alcohol. Children with disrupted attachment and trauma history have very similar symptoms to children with FASD. When prenatal alcohol exposure and trauma history collide; it often results in more severe impact on the child's functioning [18]. Children with attachment difficulties often experience caregiver proximity as threatening; an aggravating factor well understood by many participants:

> I believe, honestly that me taking over as his teacher was also having great effect on our relationship because we were still struggling with attachment and mental trauma and it is reactive attachment disorder, we have enough relational issues going on as it is and me adding on educator on that, I think just put too much pressure on our relationship.

> I would say that for a child that has an attachment disorder, being at home with the family without relief from that…and without the ability to like… decompress, is just an extremely loaded situation. And many children with attachment disorders respond in violent ways to their triggers and a lock down is a… can be of frightening and life-threatening event for a family.

Caregivers reported regression in their children related to the anxiety of the situation such as sleeping issues, eating problems, extreme separation anxiety and feeling like their pre-teens were back to being a toddler. Trauma behaviours seemed to have resurfaced for some:

> Kaitlyn's case it was anxiety, anxiety behaviours went really kind of super through the roof, and trauma behaviours that we have seen from her over the years, but that she had really done a lot of work in the last few years to work through those and move past some of that, immediately we were back there again. And she couldn't even necessarily recognize it, let alone articulate it. We could see it and know what it was. She couldn't.

Children with FASD are more vulnerable to stress and to mental health issues than the general population (reference). Furthermore, the pandemic has led to disruption in services, routine and structure, key elements to support individuals with FASD' mental health. Annette described the situation experienced by many families:

> "you had this kid who was already imploding a little bit, and then you take away all the structures, all the supports, all the predictability, everything just went…got worse, behaviours got worse, the violence and aggression got worse, his mental health just tanked and nothing was working."

Another impact on the child's mental health is the social isolation brought by physical distancing measures. The survey revealed **59%** of participants reported an increase in isolation. During interviews, many caregivers reported that their child was already struggling socially, however, the pandemic increased the social challenges.

> I guess the other thing I would say is the lack, because he's an only child and he lives only with adults, again, positives and negatives about it, but I think developmentally wise it hasn't been great for him because he didn't… he could go like literally months without seeing a child, especially when the playgrounds were closed and there was… it was, you know…so we'd be outside walking with him and he might not ever see another child for like weeks on end.

School closure

The social isolation was particularly exacerbated due to school closure. While school was identified by caregivers as a major source of stress for their children it was also a source of respite for themselves and for their children who benefited from the social aspect and structure provided by the schools. Many caregivers worry about the educational and social needs of their children being negatively impacted by school closure. However, some have benefited from having online individual support or thrived with online learning. Experience in regard to school closure was quite varied and showed how unique the needs of children with FASD can be. One caregiver in particular summarized very well how school closure and the loss of other supports has affected her children even if school is additionally stress inducing.

> So literally occupational therapy disappeared, speech therapy disappeared, psychotherapy disappeared, all of the supports around us and the core structure for our kids of school, that even though school is hard for our guys and for Kaitlyn, it's still predictable and routine, and they know what to expect and it just all disappeared overnight. And for brains that thrive on structure and routine, and all of that, it sent everybody off the deep end and it was one thing when it was two weeks.

The caregiver

Caregiver Mental Health

The impact of the children's challenging and dangerous behaviours have severely impacted the mental health of many participating caregivers. The survey indicated an increase in mental health concerns at the same time that the families experienced a reduction in social services.

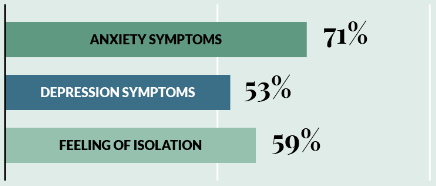
Two caregivers reported having Post-Traumatic Stress Disorder as a result of caring for their child and many had to access mental health support for themselves. While caregivers reported needing mental health counselling to get through the challenges, some were receiving this support, and some felt that their needs were overlooked:

> I'm trying not to have this fear and I'm trying to let it go and I'm actually had a counselor helping me with it, because in all honesty, caring for Christine has created mental abuse for me and I have PTSD. And sometimes I feel that that's overlooked, right? Because the services are Christine's services. They're not mine.

Caregivers who responded to the survey reported an increase in depression symptoms (53% of participants), anxiety symptoms (71% of participants) and feeling of isolation (59% of participants).

Caregivers reported being exhausted by having to provide constant supervision and expressed a need for respite and mental health support.

Many caregivers reported increased symptoms of anxiety, depression and isolation during this time.



No break from the child

While most participants were dealing with an increase in child to caregiver violence and aggression, creating mental health concerns, they also found themselves exhausted by the lack of respite. Many also spoke of the need for constant supervision of their teenagers due to the nature of their needs and unsafe behaviours. “We need eyes on him all the time”, a caregiver mentioned in regard to the worry that their child will self-harm again.

> You asked about Elliott and I, we’re fucking exhausted, sorry to whoever's transcribing, but we were fucking exhausted because it was always on, 24/7.

Respite is a challenge for families impacted by FASD outside a pandemic, but this situation has put caregivers in a situation where they had to choose between respecting social distancing measure or having a respite break for the well-being of their family. Several participants are at higher risk of COVID-19 complications due to their age, disability or health conditions so finding the right respite provider was consequently complex.

Caregivers asked to have trusted options for respite and adapted to their needs and their child’s need. For example, two caregivers relied on online websites to find respite. Another respite option discussed by several caregivers (n=3) was CHEO special respite program during the pandemic. However, all caregivers said that having a 3-hour break twice during the whole pandemic was clearly not enough. One caregiver described having to drive long distance to access respite care only to end up just sleeping in her car while her son was there.

Even for families who have adopted from Children’s Aid Society, respite was very difficult to access and was provided as a last resort to avoid having the child go back into care.

> We were looking at like the…considering a temporary care agreement and… because things were feeling so unsafe in our home during COVID and the other option was or was never an option presented to me...I asked for respite and they agreed to it, and they made sure to let me know many, many times that it was not something that they do and that they did it anyways.

Placement instability

Three families reported having their adoption placement in "limbo" including one whose child was not living in their home during the time of the interview. Increase in their child's challenging behaviours and dangerous behaviours compounded with not having any respite and the loss of their regular source of supports has led families already in crisis to be pushed over the edge.

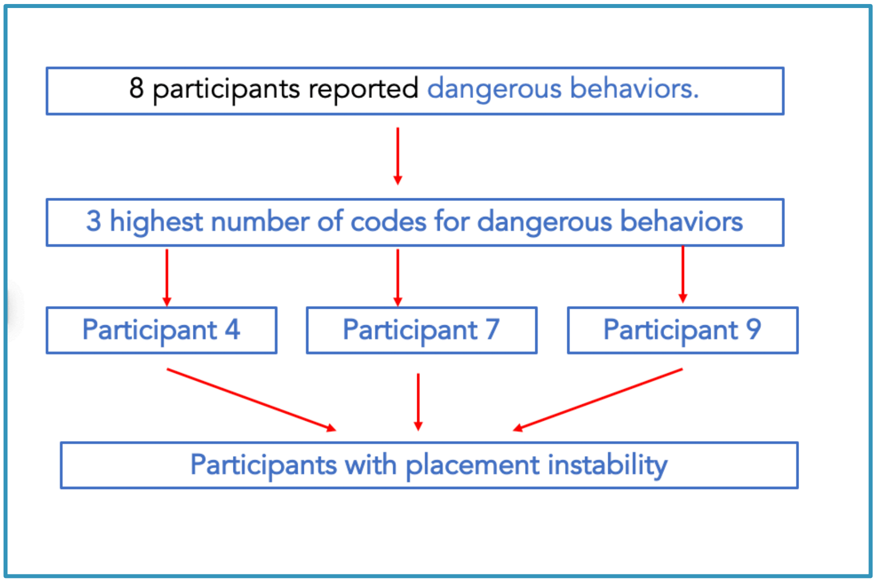
> I don't know that we make it through this. I've never in 11 years, never seriously thought that we would ever talk about adoption disruption, ever. And we did this summer.

Two of the families are also expressed deep concern for the other children living in the home:

> My son is…has been expressing, like expressing more signs of being traumatized by some of what has happened and I'm not willing to…to have that continue.

A review of the interview data showed that the three families considering a placement for their child also had the highest number of codes for dangerous behaviours as reported by the caregivers. This may reflect that increasing dangerous behaviours can lead to placement instability.

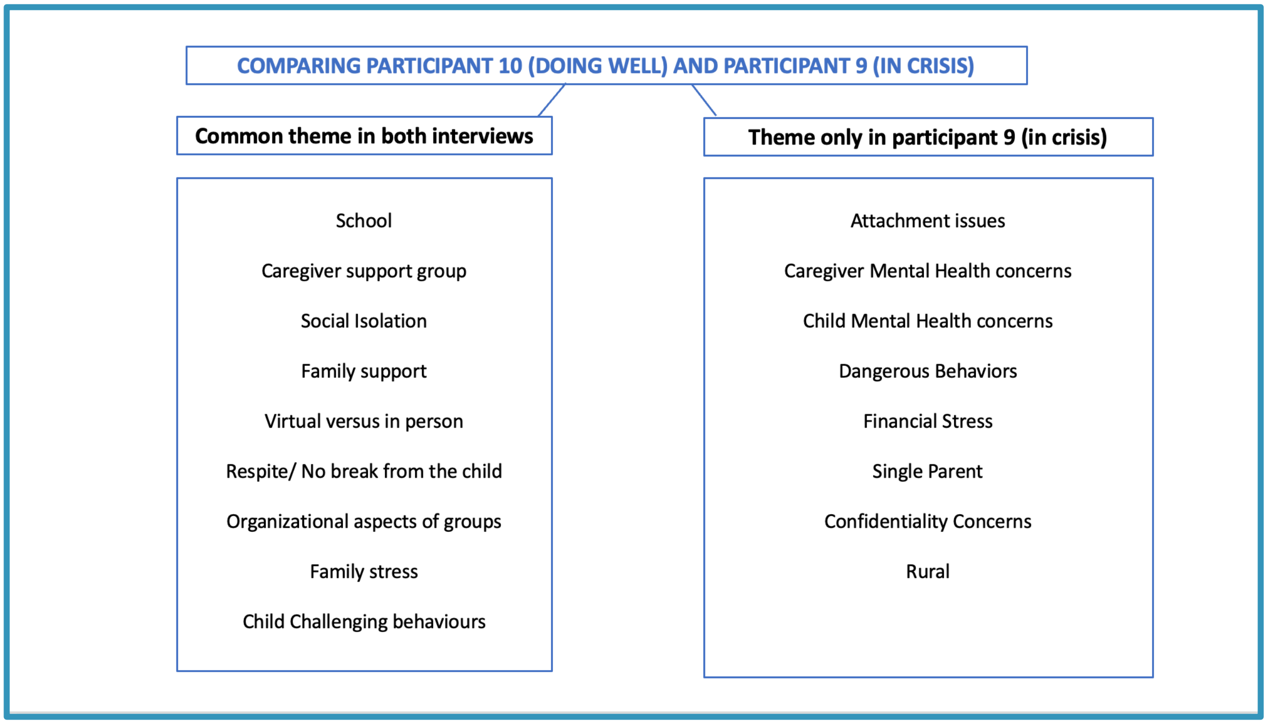
Figure 2: Dangerous Behaviours corelated with placement instability



One more demographic commonality for families with placement instability was the rural aspect. Something that was mentioned by the three of them was a challenge in accessing services for their child such as crisis support, respite and mental health support. One rural caregiver even reported considering moving closer to Ottawa to have better access to needed services.

To capture the main differences of themes mentioned by a participant reporting "doing well" versus a participant considering a new placement for their child (in crisis), a comparative analysis was conducted using NVivo. Below is a comparison of P10 (doing well) and P9 (placement instability). P6 has themes not seen in P10 such as financial stress, attachment issues, child dangerous behaviours, as well as child and caregiver mental health, rural, single caregiver. These factors may contribute to the severity of the crisis or may at times be a consequence of the child's struggles.

Figure 3: Caregiver reporting doing well versus not doing well.



The services

GENERAL SATISFACTION

All participants who accessed virtual services were satisfied with the overall service delivery, and thankful for the continued support ABLE2 has provided despite the circumstances. Several caregivers emphasized particular appreciation for the support they had received from individuals who work at ABLE2. This included daily check-ins with youth in crisis, one-to-one support and direction towards available resources. The flexibility demonstrated in terms of service delivery methods and availability of the staff was mentioned by many.

FAMILY SUPPORT

Satisfaction

Most caregivers reported they were currently communicating with their FASD workers by phone and were happy with this method of delivery. Although Email was also used, most participants expressed a preference to communicating over the phone or on Zoom to allow for more in-depth conversations. Multiple caregivers said they found ABLE2 helpful in directing them towards resources and responsive to their needs.

Suggestions and recommendations

One participant suggested organized family activities would be beneficial for social interaction for both caregivers and children. On this note, a caregiver said they hoped to see the webinars expanded, and recordings of these sessions available online as a library of educational tools for community members.

> “Not that necessarily I would always be watching them, but it would really be helpful for me to give that information to other people who are working with Joe and say, hey, here's a list, you know, watch them or don't watch them, but they're only an hour and it'd be really helpful for you, I think.”

CAREGIVER SUPPORT GROUP

Satisfaction

Three interview participants expressed not enjoying support groups in general regardless of the method of delivery. For others, participating in these groups provided opportunities to connect with others despite the restrictions on gathering.

> "I needed it to cope, it was an absolute necessity. If the lockdown happened and our in-person groups just ended until after…I don't know what I would have done…"

Eight participants from the interviews said they would like to have the option to continue with virtual support groups. Two were interested in only virtual support groups, while six were in favor of a hybrid model between virtual and in-person delivery. From the survey, **18%** of respondents indicated that they would prefer to continue with a virtual support group after social distancing measures end, whereas **59%** indicated they would sometimes, and **24%** indicated they would not.

Virtual support groups were described as more convenient than in-person meetings. Not having to drive to the groups, and therefore having to dedicate less time weekly to access the services, was mentioned most frequently as a reason for preferring virtual groups. From the survey, **45%** listed no commute as the largest advantage to virtual services. Additionally, not having to find childcare was considered advantageous. Other reasons for preferring the virtual support group included meeting people you would not otherwise meet and being able to decide last minute whether to attend. The lack of a personal connection was mentioned most frequently as a drawback to the virtual support group.

Those living in rural areas were more likely to suggest commute time as a benefit to virtual services. Some participants in rural areas found WIFI access a barrier to accessing these groups.

Confidentiality concerns were related to the security of the online group and privacy in the home. Three participants said they were less comfortable sharing personal details over Zoom compared to in-person. However, several participants appreciated that ABLE2 had a statement before each group session to explain confidentiality rules, which seemed to put their minds at ease.

Table 3: Pro and Cons of virtual support group from interviews and survey

Virtual Caregiver Support Group			
Pros		**Cons**	
Not having the find childcare	3	Lack of personal connection	7
No commute/less total time commitment	7	Wifi and technology issues	5
		Confidentiality	3

Half of the caregivers interviewed found support groups with too many participants to be overwhelming and believe smaller groups would be more conducive to a natural dialogue. These individuals suggested that the ideal group size would be 4-7 participants. One participant mentioned evenings as the preferred for time of day of the group. Another stated that they relied on the groups being held once per week and did not want them to be offered less frequently. Two participants indicated that they preferred a support group with more focus and educational components.

YOUTH SUPPORT GROUP

Satisfaction

From the interviews, three caregivers had children who consistently participated in the youth support group. One participated in the young adult support group and said it was the highlight of their week, due to the social connections formed. Another caregiver whose teenager enjoyed the youth group said they believed this was possible because she had a relationship with the leader of the group beforehand.

Suggestion

An issue mentioned by several participants is the difficulty of many youth with FASD to identify with this diagnosis. This restricts their attendance to the group. Another challenge brought up by two participants is the age of the child. A mother of a young child talked about the difficulty that younger children have in participating with online groups. She suggested that children who are not able to participate in virtual groups could receive an individualized phone call on a regular basis. Caregivers of teenagers also spoke about many suggestions for the youth groups such as smaller numbers (2-3) of children around the same age, buddy programs and mentorship. Other ideas for services targeted towards youth were specific life skills trainings such as cooking, self-care or sex education.

Another obstacle to participation in the youth group identified by some caregivers was that they could not trust their child to be unsupervised online, therefore the caregiver had to be present in the room during the virtual youth group.

Recommendations

Specific recommendations for ABLE2

This study was aimed at assessing client satisfaction with the services offered by ABLE2 as service delivery moved from in-person to virtual. Overall, clients showed high levels of satisfaction and had many positive comments to make about the program. The dedication of the staff, flexibility in adapting services to the needs of the family and the importance of the relationship they have built with them over time were highlighted by many.

The survey and interview data identified some specific suggestions made by clients:

- Organized family activities when COVID-19 will allow.
- Webinars expanded to have a library of available information for community members.
- Smaller caregiver support groups offered and possibly divided by concerns such as justice issues or dangerous behaviours.
- When in-person meetings resume, a hybrid model of online and in-person should be available.
- The youth support group could be renamed for teenagers who don't identify with the FASD diagnosis.
- If the child is too young to participate effectively in online groups, phone calls from a worker could be considered if requested by the caregiver.
- Life skills trainings and mentorship could also be considered as part of the youth specific services.

Barriers to access

FARP primarily serves foster, kinship and adoptive families. The demographic represented raises a concern about vulnerable families, such as biological mothers raising their child with FASD who are facing similar issues without the support required. Unfortunately, FASD stigma often acts as a barrier for biological mother to access FASD specific services [19]. ABLE2 and FARP could reflect on this possible barrier to access for biological families and explore ways to make access easier. It is possible that the name of the program and the staff role (FASD Worker) may be a drawback for these families.

Aggression displayed by children towards family members

While not all families impacted by FASD will experience child to caregiver aggression, the interview data clearly indicated an increase in dangerous in the home during the pandemic. Eight out of ten families in our study reported experiencing this issue. This finding is alarming and necessitates an urgent response. Aggression of children towards parents is also one of the main causes of adoption disruption [20] and this study suggested that a high level of dangerous behaviours correlated with placement instability.

ABLE2 could reflect on how they might respond to this pressing issue. Whereas research on this issue in Canada is scarce, the United Kingdom has several research studies and intervention models in place to respond to this issue [21,22]. For example, Non-Violent Resistance (NVR) is a form of treatment for aggressive and violent behaviour in children and young people., NVR is a multi-modal systemic, family- and community-based form of intervention for serious behaviour problems in young people, for harmful and self-destructive behaviour, for self-harm, and anxiety disorders [21,22]. This model doesn't use a behavioural approach, but rather is trauma-informed and attachment focused. Therefore, this model could possibly be adapted by FARP as an intervention when supporting families. It is also a model being implemented by FARP's partner, Adopt4Life.

Systemic recommendations

The results of this research study highlight the high level of support required by families raising children with FASD. Previous studies have described the experience of caregiving for children with FASD as very stressful [8,11,13] This research study identified several specific needs of these families; timely mental health support for caregivers, crisis support 24/7 and respite services. These services should be FASD and trauma informed. A special concern for rural families was identified where these services are even more scarce.

Respite

Previous studies have described the importance of respite for families impacted by FASD [8,13]. As mentioned above, this service may be a critical factor for keeping the child in the home. During COVID-19, safe respite options should be offered to families. Participants asked for respite options from trusted sources that are FASD informed, offered on a regular basis and of sufficient duration to be effective.

Mobile crisis unit

The loss of the mobile crisis unit was mentioned by families as this service was replaced by law enforcement intervention. As caregivers stated, this has not been an adequate community response. We strongly recommend that the mobile crisis unit resumes as an essential service. First responders should also be trained in de-escalation techniques that are trauma and FASD informed.

Mental Health Intervention

Several caregivers have been diagnosed with Post-Traumatic Stress Disorder and other mental health issues as a consequence of their caregiving experience. Some may also struggle with preexisting trauma or mental health conditions. Regardless, it appears critical that mental health support be provided to address their needs. Family support offered by FARP is a great way to help families, but specialized therapeutic treatment may be required and should be available to families. Research has consistently shown that mental health concerns in the caregiver severely affect their child's mental health and their attachment relationship [23]. A stable and nurturing home is also the main factor in preventing secondary impacts of FASD [24].

References

1. Lucyna M. Lach, Dafna E. Kohen, Rochelle E. Garner, Jamie C. Brehaut, Anton R. Miller, Anne F. Klassen & Peter L. Rosenbaum (2009) The health and psychosocial functioning of caregivers of children with neurodevelopmental disorders, Disability and Rehabilitation,31:9, 741–752, DOI: 10.1080/08916930802354948
2. Houting., J. Stepping Out of Isolation: Autistic People and COVID-19. Autism in Adulthood. Ahead of print. https://doi.org/10.1089/aut.2020.29012.jdh
3. Emerson, E., Hatton, C. (2007). Mental Health of children and adolescent with intellectual disabilities in Britain. British Journal of Psychiatry, 191 (6), 493–499
4. United Nations, A Policy Brief, A Disability-Inclusive response to COVID-19, May 2020. https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2020/05/sg_policy_brief_on_persons_with_disabilities_final.pdf
5. Hirvikoski T, Mittendorfer-Rutz E, Boman M, Larsson H, Lichtenstein P, Bolte S. Premature mortality in autism spectrum disorder. Br J Psychiatry. 2016; 208(3):232–238.
6. Palacios, J., Rolock, N., Selwyn, J., & Barbosa-Ducharne, M. (2019). Adoption Breakdown: Concept, Research, and Implications. Research on Social Work Practice, 29(2), 130–142. https://doi.org/10.1177/1049731518783852
7. Popova S, Lange S, Shield K, et al. Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis. Lancet. 2016; 387(10022):978-987. doi:10.1016/S0140-6736(15)01345-8
8. Watson SL, Hayes SA, Coons KD, Radford-Paz E. Autism spectrum disorder and fetal alcohol spectrum disorder. Part II: a qualitative comparison of caregivering stress. J Intellect Dev Disabil. 2013; 38(2):105-113. doi:10.3109/13668250.2013.788137
9. Anderson T., Mela M., Stewart M.· The implementation of the 2012 mental health strategy for Canada through the lens of FASD. Revue canadienne de santé mentale communautaire, 2017, 36 (Special Issue): 69-81, https://doi.org/10.7870/cjcmh-2017-031
10. Smith, J., Flowers, P., Larkin, M. (2009). Interpretative Phenomenological Analysis (SAGE)
11. Sanders, J. L., & Buck, G. (2010). A long journey: Biological and non-biological caregivers'

experiences raising children with FASD. Journal of Population Therapeutics and Clinical Pharmacology. https://doi.org/10.1088/0957-0233/25/7/075503

12. Popova, S., Lange, S., Shield, K., Mihic, A., Chudley, A. E., Mukherjee, R. A. S., … Rehm, J. (2016). Comorbidity of fetal alcohol spectrum disorder: A systematic review and meta-analysis. The Lancet. https://doi.org/10.1016/S0140-6736(15)01345-8

13. Phung, M. H., Wallace, L., Alexander, J., & Phung, J. (2011). Caregivering Children with Fetal Alcohol Syndrome Disorders (FASD). Retrieved from http://www.webmedcentral.com/article_view/1638ArticleURL:http://www.webmedcentral.com/article_view/174

14. Phoenix, M. Children with disabilities face health risk, disruption and marginalization under coronavirus. The conversation. https://theconversation.com/children-with-disabilities-face-health-risks-disruption-and-marginalization-under-coronavirus-137115. May 11, 2020

15. Kendall-Tackett K., Lyon T., Taliaferro G., Little L. Why child maltreatment researchers should include children's disability status in their maltreatment studies. Child Abuse & Neglect 29 (2005) 147–151

16. Cottrell, B., & Monk, P. (2004). Adolescent-to-Caregiver Abuse: A Qualitative Overview of Common Themes. Journal of Family Issues, 25(8), 1072–1095.

17. Svetlana Popova, Shannon Lange, Larry Burd, Jürgen Rehm, The Economic Burden of Fetal Alcohol Spectrum Disorder in Canada in 2013, Alcohol and Alcoholism, Volume 51, Issue 3, 1 May 2016, Pages 367–375, https://proxybiblio.uqo.ca:2069/10.1093/alcalc/agv117

18. Price, A., Cook, P. A., Norgate, S., & Mukherjee, R. (2017). Prenatal alcohol exposure and traumatic childhood experiences: A systematic review. Neuroscience and Biobehavioural Reviews, 80(May), 89–98.

19. Emily Bell, Gail Andrew, Nina Di Pietro, Albert E. Chudley, James N. Reynolds, Eric Racine, It's a Shame! Stigma Against Fetal Alcohol Spectrum Disorder: Examining the Ethical Implications for Public Health Practices and Policies, Public Health Ethics, Volume 9, Issue 1, April 2016, Pages 65–77,

20. Selwyn, J., & Meakings, S. (2016). Adolescent-to-Parent Violence in Adoptive Families. British journal of social work, 46(5), 1224–1240.

21. Omer, H. (2004). Nonviolent resistance. A new approach to violent and self-destructive behaviour. New York: Cambridge University Press.

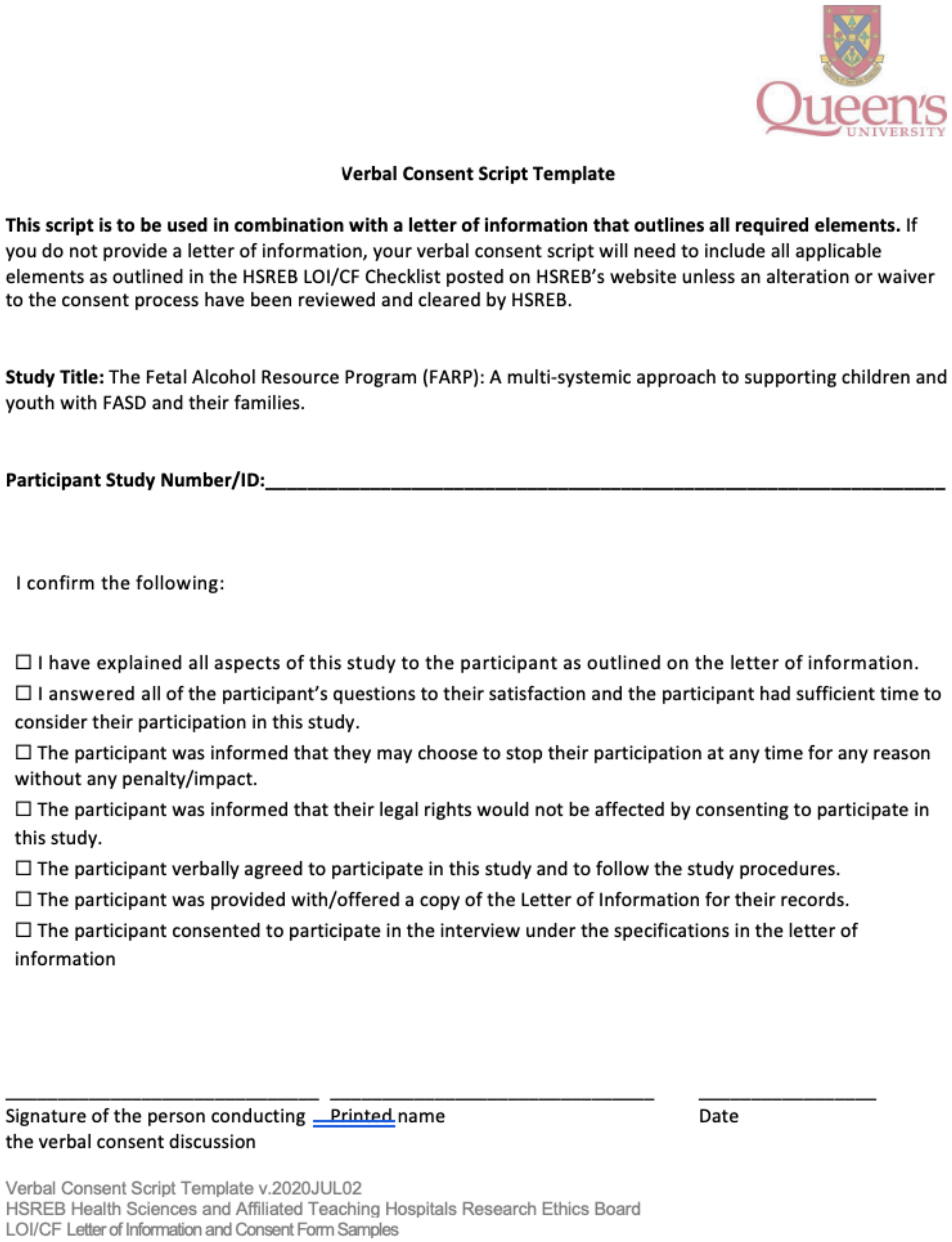
22. Jakob, P. (2019). Child-focused family therapy using non-violent resistance: hearing the voice of need in the traumatized child. In E. Heismann, J. Jude & E. Day (Eds.), Non-violent Resistance. Innovations in Practice. (pp. 51-63). Hove: Pavilion Publishing and Media.

23. Russell, B. S., Hutchison, M., Tambling, R., Tomkunas, A. J., & Horton, A. L. (2020). Initial Challenges of Caregiving During COVID-19: Caregiver Burden, Mental Health, and the Parent–Child Relationship. Child Psychiatry and Human Development, 51(5), 671–682.

24. Streissguth, A., Bookstein, F. ., Sampson, P., Barr, H. M., O'Malley, K., & J.K., Y. (2004). Risk factors for adverse life outcomes in Fetal Alcohol Sydnrome and Fetal Alcohol Effects. Journal of Developmental and Behavioural Pediatrics.

25. Hughes, D. A. (2000). Facilitating developmental attachment: The road to emotional recovery and behavioral change in foster and adopted children. Jason Aronson, Incorporated.

APPENDIX 1 : Verbal consent form



Queen's UNIVERSITY

Verbal Consent Script Template

This script is to be used in combination with a letter of information that outlines all required elements. If you do not provide a letter of information, your verbal consent script will need to include all applicable elements as outlined in the HSREB LOI/CF Checklist posted on HSREB's website unless an alteration or waiver to the consent process have been reviewed and cleared by HSREB.

Study Title: The Fetal Alcohol Resource Program (FARP): A multi-systemic approach to supporting children and youth with FASD and their families.

Participant Study Number/ID:____

I confirm the following:

☐ I have explained all aspects of this study to the participant as outlined on the letter of information.

☐ I answered all of the participant's questions to their satisfaction and the participant had sufficient time to consider their participation in this study.

☐ The participant was informed that they may choose to stop their participation at any time for any reason without any penalty/impact.

☐ The participant was informed that their legal rights would not be affected by consenting to participate in this study.

☐ The participant verbally agreed to participate in this study and to follow the study procedures.

☐ The participant was provided with/offered a copy of the Letter of Information for their records.

☐ The participant consented to participate in the interview under the specifications in the letter of information

______________________________	______________________________	_______________
Signature of the person conducting the verbal consent discussion	Printed name	Date

Verbal Consent Script Template v.2020JUL02
HSREB Health Sciences and Affiliated Teaching Hospitals Research Ethics Board
LOI/CF Letter of Information and Consent Form Samples

APPENDIX 2: Consent form for qualitative interview

FAMILY CONSENT FORM

PROJECT TITLE: Responding to the COVID-19 pandemic challenges for families with children impacted by Neurodevelopmental Disorders

Principal Investigator:

Dr. James N. Reynolds, PhD

Professor

Department of Biomedical and Medical Sciences

Queen's University

613-533-6000 ext. 77562

jnr@queensu.ca

A research team member will read through this consent form with you, describe the project in detail, and answer any questions you may have.

FUNDING AND ETHICS

This study is funded by MITACS and Kids Brain Health Network (KBHN). It has been reviewed for ethical compliance by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

CONFLICT OF INTEREST STATEMENT

The researchers declare that they have no conflict of interest, nor will they receive any personal benefit from this research project.

INVITATION AND BACKGROUND INFORMATION

You are invited to provide information about your experience as a caregiver of a child with a neurodevelopmental disability; more specifically about your needs during the COVID-19 pandemic as well as your experience of the virtual services provided by ABLE2 (Formerly Citizen Advocacy Ottawa). The aims of the study are to make recommendations to adapt ABLE2's services to the needs identified by caregivers, and to improve accessibility to and satisfaction with the different services provided such as virtual training, virtual support groups and virtual family support services. The data gathered in this study will also provide evidence to inform further policy. This specific study is part of a broader research program to assess the quality and the impact of the services provided by Citizen Advocacy Ottawa.

WHAT IS INVOLVED?

The study will take place over 4 months. You are asked to contribute to this research by answering questions from your perspective as a caregiver about your family situation and your experience of ABLE2's services.

CONFIDENTIALITY

All information obtained during this study is strictly confidential and your identity will be protected at all times. To be sure you and your family's identities are protected, we will use alphanumeric labels instead of names. Any personal information collected will be stored in locked files and will be available only to Dr. James Reynolds, Maude Champagne and the research team. You and your family will not be identified in any written reports. The staff at ABLE2 will only have access to the final summary report; not the individual interview transcripts.

VOLUNTARY PARTICIPATION

Your participation in this study is voluntary. You may withdraw from this study at any time and without problems or effects to future care or access to services provided by ABLE2.

The study investigators may take you out of the study if:

- Staying in the study would be harmful.
- The study is cancelled.
- There may be other reasons to take your family out of the study that we do not know at this time.

POSSIBLE BENEFITS AND RISKS

During the study, you will be asked questions about your family and your child. This may make you feel some discomfort or wariness. We will provide support in the case of any upsetting event. This may include speaking to a trained counsellor.

While there are no known direct benefits from your participation in this study, your contribution will help ABLE2 improve its services and continue advocating for the benefits of individuals with neurodevelopmental disabilities.

PARTICIPANT STATEMENT AND SIGNATURE SECTION

I have read and understand the consent form for this study. I have had the purposes, procedures and technical language of this study explained to me. I have been given sufficient time to consider the above information and to seek advice if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this consent form for my information.

If at any time you have further questions, problems or adverse events, you can contact Dr. James Reynolds (613-533-6000, ext 77562), or the Head of the Department of Biomedical & Molecular Sciences, Dr. Lynne-Marie Postovit (613-533-2600). If you have any concerns about your rights as a research participant please contact the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at 1-844-535-2988 or HSREB@queensu.ca. The Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (HSREB) may require access to study-related records to monitor the ethical conduct of the research.

By signing this consent form, I am indicating that I agree to participate in this study.

Primary caregiver (Participant, please sign) Date

Legal Guardian (Please sign again if necessary) Date

Signature of Person of Conducting the Consent Discussion Date

INVESTIGATOR

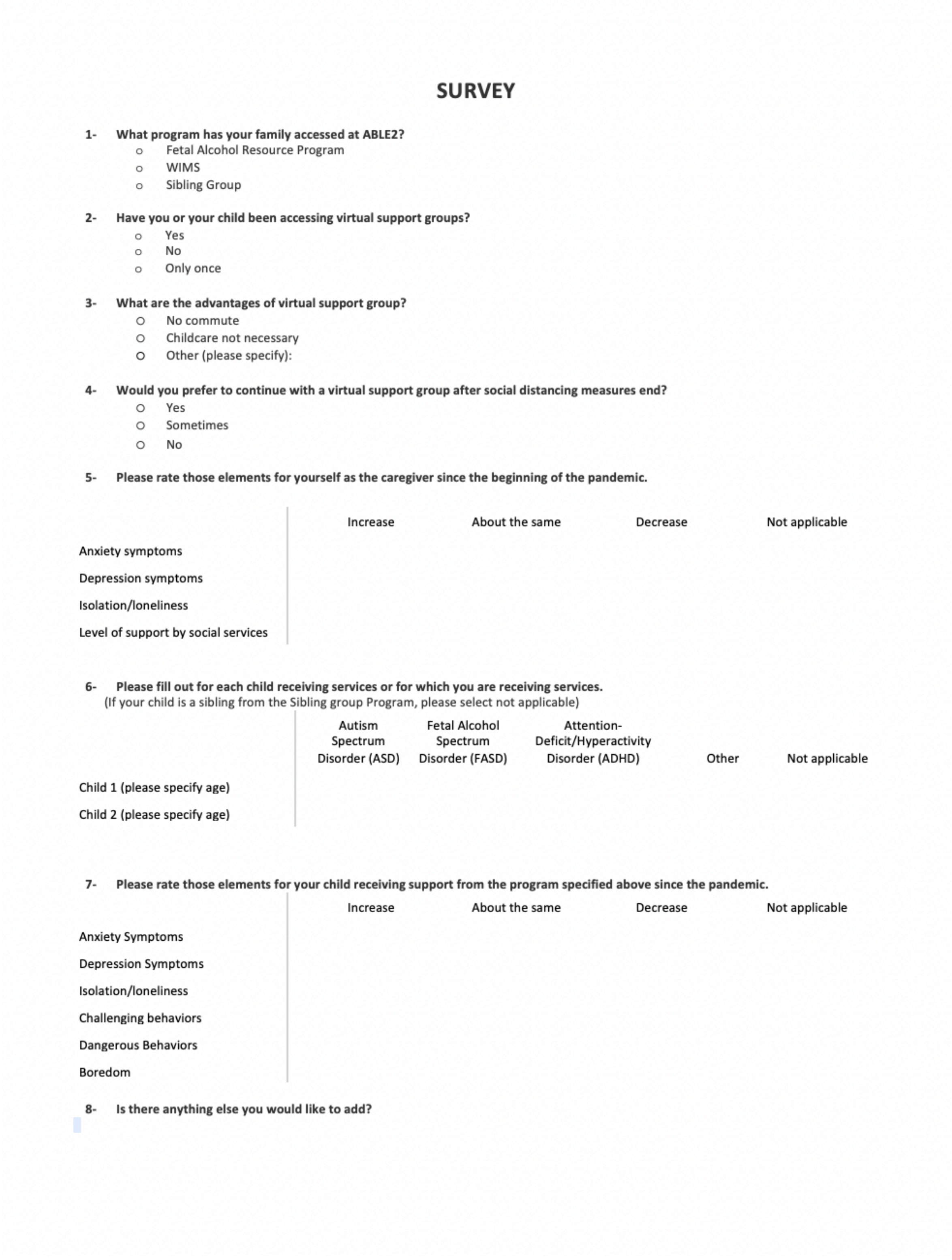
I, or one of my colleagues, have carefully explained to the participant the nature of the above research study. I certify that, to the best of my knowledge, the participant understands clearly the nature of the study and demands, benefits and risks involved to participants in this study.

Signature of Principal Investigator (or delegate) Date

APPENDIX 3: Qualitative interview questions

hen did you start using FARP family support service?	⇒ Before or after COVID-19
ease describe how COVID-19 has impacted your family?	⇒ Increase in stress / anxiety ⇒ depression ⇒ dangerous behaviours ⇒ mental health issue ⇒ decrease in services ⇒ boredom ⇒ financial impact ⇒ work ⇒ siblings relationship ⇒ anything positive
w is your general experience of the **virtual (versus in person)** family support?	
hat are some of the benefits (compared with in-person support)?	
hat are some of the disadvantages?	⇒ Accessibility concerns ⇒ wifi ⇒ privacy
hat are some suggestions you would have to improve the services?	
e you planning on continuing receiving virtual services after the pandemic is over?	
e there any support services your family would need in relation to your child with FASD that FARP is not currently providing?	
ould you like to add anything else?	

APPENDIX 4 : Survey questions



SURVEY

1- **What program has your family accessed at ABLE2?**
- ○ Fetal Alcohol Resource Program
- ○ WIMS
- ○ Sibling Group

2- **Have you or your child been accessing virtual support groups?**
- ○ Yes
- ○ No
- ○ Only once

3- **What are the advantages of virtual support group?**
- ○ No commute
- ○ Childcare not necessary
- ○ Other (please specify):

4- **Would you prefer to continue with a virtual support group after social distancing measures end?**
- ○ Yes
- ○ Sometimes
- ○ No

5- **Please rate those elements for yourself as the caregiver since the beginning of the pandemic.**

	Increase	About the same	Decrease	Not applicable
Anxiety symptoms				
Depression symptoms				
Isolation/loneliness				
Level of support by social services				

6- **Please fill out for each child receiving services or for which you are receiving services.**
(If your child is a sibling from the Sibling group Program, please select not applicable)

	Autism Spectrum Disorder (ASD)	Fetal Alcohol Spectrum Disorder (FASD)	Attention-Deficit/Hyperactivity Disorder (ADHD)	Other	Not applicable
Child 1 (please specify age)					
Child 2 (please specify age)					

7- **Please rate those elements for your child receiving support from the program specified above since the pandemic.**

	Increase	About the same	Decrease	Not applicable
Anxiety Symptoms				
Depression Symptoms				
Isolation/loneliness				
Challenging behaviors				
Dangerous Behaviors				
Boredom				

8- **Is there anything else you would like to add?**