

Research Brief: Supporting Children with Special Needs and their families

A summary of the research on how to best support children and youth with special needs and their families during COVID-19, including tips and resources

Under normal circumstances, it can be difficult for families who have children with special needs to find mental health supports. The ministry is hearing that the impact of isolation as a result of COVID-19 has been even more profound for these families. They are experiencing a lot of additional stress because their kids would normally be in school and receiving developmental supports. The ministry would like to ensure that it is doing everything it can to help these families and would like to understand the landscape of resources that may be available.

This Research Brief reviews recent academic and grey literature to address the following questions:

- What does the literature say about how best to support parents who have children with special needs during this time of COVID?
- Are there tips or resources for parents on how to support their child's developmental needs during this time when they are not in school or child care?
- Are there tips or resources for these parents to support their own wellbeing during this time?
- Are there tips or resources available for children with special needs to support their mental health during this time?
- Are there any tips of resources available for Indigenous children and families related to the above topics?

Methodology

The Strategic Policy, Research and Engagement (SPRE) team consulted with MCFD leadership to develop the research questions, and then provided them to the Health and Human Services library. Librarians conducted a search for relevant academic and grey literature. The search results were provided to SPRE, who reviewed the abstracts and requested relevant articles from the library through inter-library loan when required.

SPRE reviewed each article and pulled out key points in answer to each of the research questions. The researchers reviewed all of the content in the table to identify themes and gaps in the literature, key articles, and to write the content to follow.

The information was gathered from various organizations across Canada, serving diverse disabilities including autism spectrum disorder (ASD), Fetal Alcohol Spectrum Disorder (FASD), and speech and language disorders, as well as general child development organizations and mental health organizations.



1. Supporting Children and Youth with Special Needs during COVID-19
2. Caregiver Mental Health and Self-Care

The pandemic of COVID-19 can be stressful for parents as they are alone to care for their children with special needs (Narzisi, 2020). Ashbury et al. (2020) describe that 'children with special needs and their families are likely to be at greater risk of experiencing poor mental health and to be under substantially greater pressure, than less vulnerable families during COVID.' This brief summarizes main themes through many resources, tip sheets, articles for caregivers to support children and youth with special needs and caregiver self-care.

1. Supporting Children and Youth with Special Needs during COVID-19

Different Roles and Routines

Changes in routine and roles can be difficult for children with special needs during COVID-19. Parents are filling the role of teacher at home and children become co-learners with siblings, both being challenging adjustments for children to make. With different routines and rules, new behaviours may arise and children should be encouraged to have flexible thinking about these adapted rules and roles (Autism Parenting, 2020; Tarbox et al., 2020). One way for caregivers to demonstrate to children what it means to have different roles is to talk about objects that can have different functions (ie. a bucket can be used as a drum, to carry things, etc.) and how people play multiple roles (ie. Son, student,

friend, brother) to demonstrate in concrete ways what it means to have different roles. Parents can also use specific spaces for tasks (ie. this room is for school) to differentiate.

Caregivers can set a new routine maintained throughout physical distancing, using elements of their old routine and minimizing interruptions from 'normal' routines when possible (CAN FASD Blog, 2020). Dr. Melanie Penner (2020) suggests for parents and children with autism to create a schedule together, thinking of activities to complete as a family and provide structure for the child. They can support a new schedule by creating a visual schedule, a first-then board (a visual tool representing the order of activities), weekly timetables and using pictures to communicate (NSPCC, 2020). Visual schedules use pictures and symbols to demonstrate what activities will happen and in what order. It can reduce anxiety for children who find it difficult to process verbal information and struggle with unpredictability (Community Child Health, 2020).

Further visual resources will be discussed below.

Maintaining Connection

Technology is an important way to foster connection, build solidarity and see familiar faces during COVID-19 physical distancing. Video technologies can be used for playdates, art and music lessons, fitness classes, and contact with classmates, friends and family (American Speech-Language-Hearing Association, 2020; Narzisi, 2020). In research by Toseeb et al. (2020), parents were asked what support would help them and their child during COVID-19. One of the types of support mentioned was the opportunities for their child to see familiar faces, helping to align with previous routines and maintain relationships.

Communicate and Explain COVID-19

Explaining what COVID is to children with special needs can be difficult. Caregivers should address the child's feelings, use developmentally appropriate language and place emphasis on preventative measures rather than risks (CAN FASD Blog, 2020). It is important to stay informed and talk to children and family members about COVID-19, while managing the amount of information and media exposure (American Psychological Association, 2020; Nicholas, 2020).

Strategies including using augmentative and alternative communication (AAC) devices, visuals and social stories can support communication.

- AAC
 - Children can be encouraged to continue using their AAC devices at home for communication (ASHA, 2020)

- Parents and educators can download [Board Maker communication reference sheets](#) for AAC devices on communication about COVID-19, at home learning, and activities including messages, and topic words
- Visuals
 - Caregivers can display reminders through visual cues, such as [handwashing pictures](#) (CAN FASD Blog, 2020)
 - The [Supporting Individuals with Autism through Uncertain Times](#) package includes social narratives, daily schedule examples and templates, visual supports for hand washing, giving people space, and explaining COVID, communication tools, inside and outside activity suggestions, and online educational resources
 - [School Closure Toolkit](#) by Easter Seals includes token boards, first/then boards, and Picture Exchange Communication System (PECS) sets in the domains of sensory activities, life skills, academics, movement activities, leisure and daily schedule options

Parents expressed that a type of support that would help is access to resources such as social stories that can be used to explain COVID 19, physical distancing and changes in routine to their child (Toseeb et al., 2020).

- [My Coronavirus Story](#)
- [My COVID-19 story](#) Cree Board of Health and Social Services of James Bay
- [What is coronavirus?](#) Autism Speaks Canada
- [We Wear Masks](#) Social Story Video

Continued Consultation with Professionals and Support Team

Continued online consultation with therapists in the child's life can help parents learn and receive coping strategies to support their child in these challenging times (Autism Parenting, 2020; Narzisi, 2020). Narzisi (2020) discusses how continuing psychotherapy through video, if children were participating before COVID-19, is important for consistency and support. Checking in with a child's teacher, school staff, therapists, and health care providers can also support the mental health of children and caregivers (American Psychological Association, 2020).

When asked about their mental health and the mental health of their child in a recent survey of almost 250 parents or caregivers of school- aged children with special needs, parents described feelings of loss as a result of COVID-19, with one theme being the loss of specialist input (Ashbury et al., 2020). Using the same survey data, Toseeb et al. (2020) found the most common type of support suggested by parents that would be helpful was specialist's professional advice during this time. This professional support offers parent's reassurance, advice for meeting the child's education and mental health needs and

guidance on creating a new routine (Ashbury et al., 2020; Toseeb et al., 2020). Therapists can also provide resources or prepare materials to explain COVID and support learning at home (Narzisi, 2020).

Structure and Activities

Integrating structure through daily life activities into uncertain times can assist in maintaining routine and keeping children busy (Narzisi, 2020). Parents stated that appropriate educational activities and resources for home learning from school would be helpful during physical distancing (Ashbury et al., 2020; Toseeb et al., 2020). When trying new activities with children, it is important to be flexible, provide choices, participate with your children and set goals (Autism Parenting, 2020).

Examples of activities to try:

- Online activities including virtual museum and zoo tours, Scholastic Learn at Home and NASA videos from [Quarantine: What to do with the kids](#) by Developmental Disabilities Association
- Performing and visual arts, animal livestream, family friendly tours including museums and virtual field trips, and mental wellbeing activities by [Ontario Caregiver Organization](#)
- Sensory activities, ideas for indoor activities such as water play, and marbled painting and physical activities from [Supporting Children with Learning Disabilities/ASD](#) (activities on pg. 9-16, 19-21)
- Online interactive, social activities and programs for the summer for children with special needs through organizations such as Easter Seals, The Miracle Project (theatre, film and expressive arts), and Stem Camp Canada from [Summer Camps Go Virtual](#) by Developmental Disabilities Association

Using positive reinforcement can support caregivers as they manage their child's behaviour (Tarbox et al., 2020). A challenge amid physical distancing is that regular reinforcers such as swimming, the playground, spending time with friends, going to the movies, may be unavailable (degli Espinosa et al., 2020). Tarbox et al. (2020) suggests, specifically for children with ASD, to focus on what reinforcers are available, bringing delayed reinforcers into the present (ex. getting good grades is a delayed reinforcer) and making abstract or verbal reinforcers more concrete.

2. Caregiver Mental Health and Self-Care

Caring for children and youth with special needs can be difficult during COVID with limited supports. When caregivers are stressed, it can limit their ability to care for their children who are also stressed and experiencing change during COVID (Community Child Health, 2020). Caregivers need to continue to attend their own needs and feelings to ensure they can care for others (The Ontario Caregiver

Organization, 2020). Practicing self-care can reduce stress and improve mental health (CAN FASD Blog, 2020).

Self-Care

Prioritizing self-care can include:

- Staying connected with others virtually (APA, 2020)
- Being present and kind to yourself (APA, 2020; CAN FASD Blog, 2020)
- Seeking help (APA, 2020)
- Joining online communities for support (NSPCC, 2020)
- Taking a break.
- Maintaining physical health, including physical activity, sleep, time outside and healthy eating (CAN FASD Blog, 2020)
- Engaging in hobbies (CAN FASD Blog, 2020)

Here is a resource that can support caregivers to prioritize self-care.

- [Caregiving in the era of COVID-19: What to expect and how to cope](#) handout

Caregivers may need to pursue further strategies for reducing stress through behavioural parenting training, mindfulness interventions, coping skills education and counselling support (CAN FASD Blog, 2020). It is also important for caregivers to be conscious of how their loneliness and stress manifests in physiological sensations so they can care for their physical and mental wellbeing (Fulmer, 2020).

Support Groups

Caregivers can join online communities for support during the pandemic (NSPCC, 2020). Support groups are available online, often specific to geographical areas.

Examples in British Columbia:

- Family Caregivers of British Columbia
 - Caregiver Support Line Toll Free 1-877-520-3267
 - [Weekly Caregivers Connect: BC's Virtual Support Group](#)
 - [Caregiver Café: Greater Victoria](#)
 - [Self-Care for Caregivers in uncertain times](#) resource
- Parent Support Services Society of BC (not specifically for children with special needs)
 - [Online Parenting Support Circles](#)
 - BC Parenting Support Line 1-877-345-9777 Open M-F 10-4
 - Grandparents Raising Grandchildren/Kinship Care Support Line 1-855-474-9777, Monday, Tuesday, Thursday, Friday from 10-2

- [Family Support Institute of BC](#)
 - Call directly, join a video chat, find a support staff

Additional Resources

- [Family Support during COVID-19](#) is a comprehensive resource includes information on funding, mental wellness, school and learning and other resources in BC.
- [Managing Anxiety and Stress in Families with children and youth during the COVID-19 Outbreak](#) produced by the Child and Youth Mental Health and Substance Use Community of Practice

Cultural and Systemic Approaches

Systemic Approaches

Phoenix (2020) discuss systemic approaches to concerns for children and youth with special needs and their families during COVID-19. This includes:

- Inclusion of people with disabilities in policy development
- Ensuring human and equipment resources are available for home and centre-based care
- Accessible information
- Promotion of social inclusion to advance mental health and child safety

Indigenous Caregiving

Andrea Landry (2020) wrote about Indigenous kinship during the pandemic, encouraging a critical perspective on viewing children as a disruption. She wrote that rather than viewing this time with children as inconvenient, a style of thinking influenced by residential schools and colonial education systems, Indigenous caregivers should remember ‘that we must begin to find new ways to help raise our children that don’t require a reliance on colonial systems’. While spending time with children at home, Indigenous caregivers can include children in all aspects of daily life, involved in traditional teachings, engage in land-based learning and lead their learning and activities.

Limitations

With unique challenges and needs as a result of the pandemic, there is limited academic research directly addressing COVID-19. When examining the research done as a response to COVID-19, it is also important to notice the potential bias in the results. Toseeb et al. (2020) identified that parents who are the most overwhelmed or have children with severe needs may not be able to complete a survey or participate in data collection, impacting the data analyzed. Future studies will need to ensure a proportionate representation in the sample.

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