



The Impact of COVID-19 on British Columbia's Children with Medical Complexity and their Families

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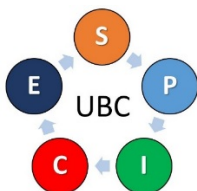
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Table of Contents

	Page
Executive Summary	3
Recommendations	4
Study Background	5
Profile of Children with Medical Complexity	6
Healthcare Usage & Impact of COVID-19	9
Education & Impact of COVID-19	11
Social Services & Impact of COVID-19	12
Profile of Survey Respondents (Parents/Guardians)	13
Impact of COVID-19 on Parents/Guardians	15
Profile of Family and Community & Impact of COVID-19	18
Conclusions	21
Acknowledgements	22



Executive Summary

Between August 4 and September 4, 2020, a web-based survey was conducted with parents/guardians of children with medical complexity (aged 0 to 18 years, inclusive) in British Columbia (BC), Canada. The purpose of the survey was to investigate the impact of the ‘first wave’ of COVID-19 and the associated restrictions on these children and their families.

Profile of Survey Respondents & their Children with Medical Complexity

The survey was completed by **156** parent/guardian respondents, who provided information about **188** children with medical complexity. Most (91.7%) of the respondents were women, specifically mothers. Their children ($N=188$) were on average 9.5 years old, and over half (58.0%) were boys. Of the 188 children reported on in the survey, **156** were school-aged.

Key Findings

Healthcare Services

- 30.3% of children’s parents avoided taking them to the Emergency Department in circumstances when they typically would have taken them.
- 63.8% of children had appointments with medical specialists cancelled or postponed by the clinic.
- The majority of children had therapies (occupational, physio, speech) decreased or stopped.

Education

- Between March 17 and May 29, 2020, 61.1% of children did not attend school at all.
- Between June 1 and the end of the 2019/2020 school year, 44.2% of children did not attend school because their parents chose to keep them at home.

Social Services

- 73 (38.8%) children’s parents were not able to access any of the initiatives introduced by the BC Ministry of Children and Family Development to offset the impact of COVID-19 restrictions.
- 72 (38.3%) children’s parents accessed flexible use of respite funds (for homemaking such as cleaning, meal preparation, and caregiver relief for siblings).
- 41 (21.8%) children’s parents accessed additional emergency relief support funding.

Family & Community Life

- Respondents, mainly mothers, indicated that they are solely responsible for their medically complex child(ren)’s care the majority of the time.
- The majority of parents ($n=89$, 57.1%) reported that their own physical health is ‘somewhat’ or ‘much’ worse than one year ago.
- The majority of parents ($n=114$, 73.1%) reported that their own mental health and social well-being are ‘somewhat’ or ‘much’ worse than one year ago.
- Household income decreased, while unemployment and reliance on food security programs increased.

Conclusion: COVID-19 and its associated restrictions have had wide-ranging (mainly negative) consequences for BC’s children with medical complexity and their families.



Recommendations

Three recommendations that cut across healthcare, education, social services and home life are:

- Transparent, timely, and effective communication.
- Broad accessibility to services and supports, particularly direct/individualized funding.
- Focus on equity and meaningful engagement.

Healthcare Services

- Create 8-1-1 services to provide access to skilled pediatric Registered Nurses and/or Nurse Practitioners with expertise in medical complexity.
- Centralize communication contact (telephone and email) for medical specialists and out-patient clinics at BC Children's Hospital for children accessing multiple clinics.
- Allow for extended refills (e.g., 90 days) for drugs under the Controlled Prescription Program.
- Review the administration of Nursing Support Services, particularly contracting of nursing hours to private companies. Similar to home support for Seniors, move responsibility for staffing in-home nursing care to health authorities and offer an individualized funding option whereby families can hire their own staff.

Inclusive Education

- Provide students with medical complexity with the necessary technology and in-home staffing supports to access and participate in education.
- Ensure meaningful outreach by school-based case managers to those students who are not attending school in-person – in particular, to assess their individualized support needs to facilitate access to learning and socialization with peers.

Social Services

- Reinstate emergency relief funding and extend it for six months, rather than three months.
- Eliminate wait-lists for direct-funded respite.
- Continue to minimize or eliminate reporting requirements for direct-funded respite and Autism Funding.
- In cases when contracted agencies are unable to fulfill their deliverables due to COVID-19 restrictions, those funds should be redirected to families. Doing so would allow families to obtain individualized therapy services for their children via service providers who accept private clients.

Family & Community Life

- Fund mental health supports provided by registered clinical counselors and psychologists for parents in the form of 1:1 or family therapy.
- Ensure the Canada Recovery Caregiving Benefit (CRCB) is accessible to parents, even those who were unemployed prior to COVID-19 due to caregiving responsibilities.



Study Background

In Canada, approximately one percent of children (aged 0 to 18 years, inclusive) are medically complex^a. Medical complexity is characterized by: the presence of complex, chronic conditions requiring specialized care, substantial health needs, functional dependence and/or limitations, and frequent healthcare usage^b. These children are high users of healthcare services (hospital, out-patient, and community-based)^c. It is estimated that, in addition to formal services, parents spend an average of 52 hours per week providing unpaid care at home^d.

These families, who are already in precarious situations, are impacted by the COVID-19 pandemic and associated restrictions in unprecedented ways. There is an urgent need for research to investigate these impacts and to develop timely policy and funding strategies to address areas of vulnerability.

What was the survey about?

The purpose of this survey was to investigate the impact of COVID-19 and associated pandemic restrictions on children with medical complexity and their families. Areas of focus included: healthcare usage, education, social services, and family and community life.

How was the survey conducted?

The survey was available to complete between August 4 and September 4, 2020 on Qualtrics, the secure survey platform used by the University of British Columbia. The criteria for respondents completing the survey were: (1) BC resident, (2) has child(ren) with medical complexity aged 0 to 18 years (inclusive) at the time of survey completion, and (3) completed the entire substantive portion of the survey.

Additional Notes

In various sections, we use “parents” as a short-hand for “parents/guardians” and other adults who responded to our survey.

Research ethics approval for the study was obtained from the University of British Columbia’s Behavioural Research Ethics Board (BREB).

^a Canadian Institute for Health Information. *Children and Youth With Medical Complexity in Canada*. Ottawa, ON: CIHI; 2020.

^b CAPHC Complex Care Community of Practice. (2018). Guideline for the management of medically complex children and youth through the continuum of care. Available at: https://static1.squarespace.com/static/59c12898e5dd5bd67174cf4e/t/5b9fab4ab8a0455bce3d372a/1537190734641/CAPHC+National+Complex+Care+Guideline+2018_final.pdf

^c Cohen, E., et al., *Patterns and costs of health care use of children with medical complexity*. *Pediatrics*, 2012. 130(6): p. e1463-e1470.

^d Romley, J.A., et al., *Family-provided health care for children with special health care needs*. *Pediatrics*, 2017. 139(1): p. e20161287.



Profile of Children with Medical Complexity

The **156** parent respondents provided information about **188** children (aged 0 to 18 years, inclusive) with medical complexity. Of the 188 children, **156** were school-aged.

Demographics of Children with Medical Complexity

The average age of the 188 children in this study was 9.5 years. Over half (58.0%) were boys. Over two-thirds (69.1%) received the Child Disability Benefit.

Age (in years) (<i>n</i> =188)	
Average	9.5
Range	0 – 18
Gender (#, %)	
Boy	109 (58.0%)
Girl	76 (40.4%)
Gender non-conforming	1 (0.5%)
Prefer not to say	2 (1.1%)
Receive Child Disability Benefit (#, %)	
Yes	130 (69.1%)
No	50 (26.6%)
Not specified	8 (4.3%)

Healthcare Status of Children with Medical Complexity

All of the 188 children were medically-complex, according to their parents/guardians^e. Over half (52.7%) had a rare disease^f as their primary diagnosis. 71.8% also had a diagnosis of Intellectual Disability, and 36.2% also had a diagnosis of Autism Spectrum Disorder.

Primary diagnosis is a rare disease (#, %)	
Yes	99 (52.7%)
No	86 (45.7%)
Missing	3 (1.6%)
# of additional diagnoses (<i>n</i> =172)	
Average	3.1
Range	0 – 33
Diagnosis of Intellectual/Developmental Disability (#, %)	
Yes	135 (71.8%)
No	53 (28.2%)
Diagnosis of Autism Spectrum Disorder (#, %)	
Yes	68 (36.2%)

^e For this report, we do not provide a list of the primary diagnoses as many are rare diseases and may unintentionally identify a child.

^f A rare disease or rare sub-type of disease is considered lifetime prevalence <1 in 2,000.



No	119 (63.3%)
Missing	1 (0.5%)
Number of Prescription Medications (n=180)	
Average	2.5
Range	0 – 12
Number of Over-the-Counter Medications (n=165)	
Average	0.9
Range	0 – 5
Number of Vitamins/Supplements (n=183)	
Average	2.2
Range	0 – 11

In terms of **functional abilities**, over half of the children walk independently without a walker (56.1%), while 27.1% are not able to weight-bear. Just over one-quarter (26.6%) are tube fed and 2.1% use a ventilator for assistive ventilation. Over one-quarter (27.1%) use Augmented and Assistive Communication (AAC) devices.

Mobility	
Not able to independently weight-bear (e.g. needs lift or caregivers to lift for transfers and uses wheelchair when moving around)	51 (27.1%)
Able to stand and transfer to wheelchair/chair	5 (2.7%)
Able to walk short distances (e.g. within the home) with a walker	5 (2.7%)
Able to walk longer distances with a walker	4 (2.1%)
Able to walk independently without a walker	97 (56.1%)
Able to physically ambulate (walk or crawl) but requires direct, arms-length supervision/support when doing so	18 (9.6%)
Other	25 (13.3%)
Uses tube feed	
Yes	50 (26.6%)
No	136 (72.3%)
Missing	2 (1.1%)
Use of Assistive Ventilation	
Bilevel Positive Airway Pressure (BiPAP)	3 (1.6%)
Continuous Positive Airway Pressure (CPAP)	10 (5.3%)
Ventilator	4 (2.1%)
Other	18 (9.6%)
Uses Augmented and Assistive Communication (AAC) devices	
Yes	51 (27.1%)
No	133 (70.7%)
Missing	4 (2.1%)



At Home Program (AHP)

The At Home Program is designed to support children with a severe disability or complex health care needs⁸. 104 (55.3%) children were on/accessed the AHP, while 84 (44.7%) children were not/did not access the AHP.

There are two types of benefits under this program: Medical Benefits and Respite Benefits.

In terms of Medical Benefits:

- 93 (89.4%) received medical benefits.

In terms of Respite Benefits:

- 71 (68.2%) children received direct-funded respite (i.e., individualized funding that the parents receive and disburse)
- 21 (20.2%) children received contracted respite (i.e., funding goes to an agency and they hire respite providers)
- 11 (10.6%) children were waitlisted for respite.

One (1.0%) child did not have a Benefit (Medical or Respite) specified.

⁸ For more information, the At Home Program Guide is available here: https://www2.gov.bc.ca/assets/gov/family-and-social-supports/children-teens-with-special-needs/at_home_program_guide.pdf



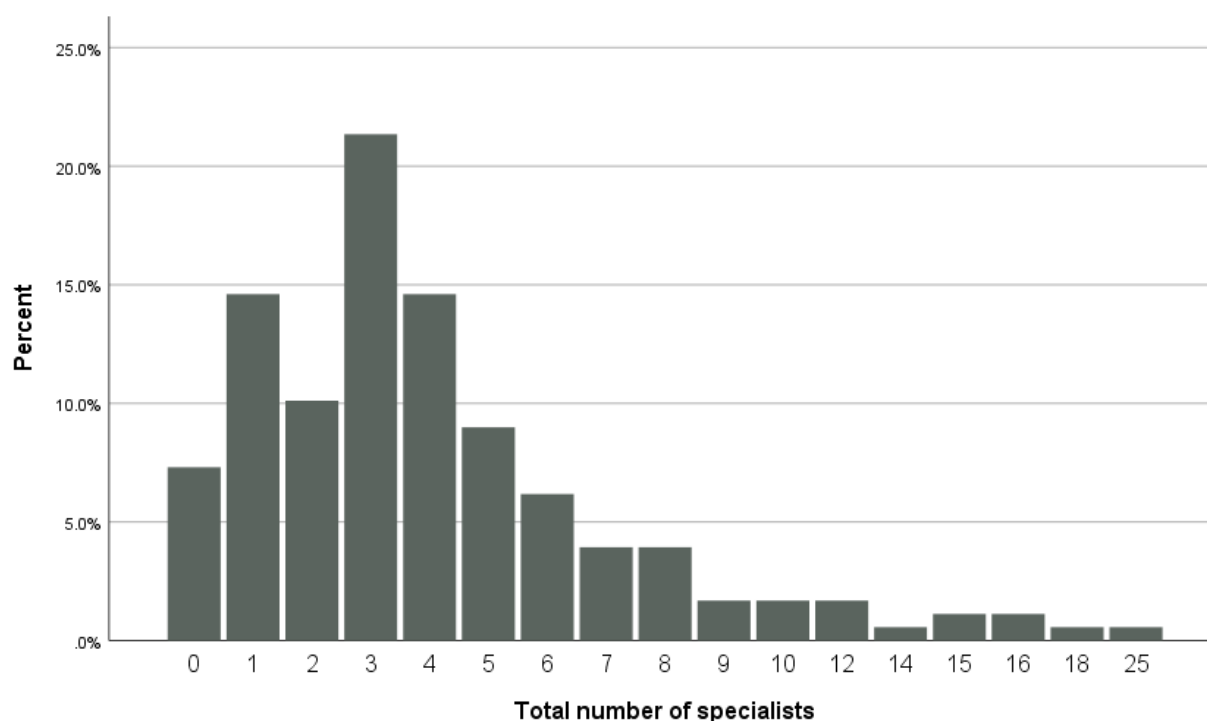
Healthcare Usage & Impact of COVID-19

Hospital Service Usage during COVID-19

- Since February 1, 2020, 57 (30.3%) children visited the emergency department/urgent care.
- Since February 1, 2020, 57 (30.3%) children's parents avoided taking them to the Emergency Department in circumstances where they typically would have taken them.
- Since February 1, 2020, 68 (36.2%) children were admitted to hospital.

Specialized Pediatric Medical Services

- Children had an average of 4.2 medical specialists (range: 0 to 25, $n=178$).



Impact of COVID-19 on Access to Specialized Pediatric Medical Services

Survey respondents could choose all the responses that applied when asked about the impact of COVID-19 restrictions since February 1, 2020 on appointments with medical specialists. They indicated:

- 120 (63.8%) of children had appointments cancelled or postponed by the clinic.
- 44 (23.4%) of children had appointments cancelled/postponed by parents.
- 120 (63.8%) of children had appointments take place as schedule by virtual/online platform.
- Only 32 (17.0%) children had their appointments take place as scheduled, in person.



Allied Health Therapy Services

Early Intervention Therapies (0-5 years) are provided through locally contracted child development centres and School Aged Therapies are funded through the At Home Program.

Prior to COVID, 92 (48.9% of 188) children were receiving physiotherapy, 107 (56.9%) children were receiving occupational therapy, and 101 (53.7%) were receiving speech and language therapy.

Impact of COVID-19 on Therapy Services

In the first wave of COVID-19, the trend was a decrease or complete stoppage of therapy services.

	Increased	Stayed the same	Decreased	Stopped
Physiotherapy (n=92)	1 (1.1%)	6 (6.5%)	31 (33.7%)	54 (58.7%)
Occupational therapy (n=107)	n/a	8 (7.5%)	36 (33.6%)	63 (58.9%)
Speech and language therapy (n=101)	n/a	12 (11.9%)	24 (23.8%)	65 (64.4%)

Nursing Support Services (NSS)

Nursing Support Services is a program available to eligible children in BC aged 0 to 18 years (inclusive) whose care requires the scope of practice of a registered nurse for some aspects of their care due to the child/youth's medically complex and fragile health needs^h.

- 27 (14.4%) of the 188 children had Nursing Support Services contracts.

Of these 27 children, prior to the pandemic:

- 11 (40.7%) were receiving their full hours of care as contracted.
- 12 (44.4%) were not receiving their full hours of care.
- 4 (14.8%) were receiving their full hours 'sometimes.'

Impact of COVID-19 on Nursing Support Services (NSS)

- 3 of the 27 children were not supported because the company contracted by Nursing Support Services was unable to provide staff per the contracted hours.
- 9 of the children's parents suspended/declined some in-home supports.
- 8 of the children's parents suspended/declined all in-home supports.
- 2 of the children had their contracted hours decreased by Nursing Support Services.

In sum, prior to the pandemic, many children with Nursing Support Services contracts were not consistently receiving their contracted support hours. Since the onset of the pandemic, this trend has worsened.

^h For more information about Nursing Support Services, please visit: <http://www.bcchildrens.ca/our-services/sunny-hill-health-centre/our-services/nursing-support#FAQs>



Education & Impact of COVID-19

Of the 188 children with medical complexity, 156 were school-aged. The most common grade levels that children were enrolled in for the 2019/20 school year were Grade 2 ($n=19$, 12.2% of 156) and Grade 8 ($n=19$, 12.2%).

Most of the children were enrolled in traditional ‘brick and mortar’ public schools ($n=113$, 72.4%), followed by independent/private Distributed Learning ($n=12$, 7.7%) and public Distributed Learning ($n=9$, 5.8%). Only one (0.6%) school-aged child did not attend school at all.

Special Education Needs Designations

Students in BC are assigned a special needs ‘designation’ or ‘category.’ⁱ Although only one designation is assigned per student per year, respondents reported that their children qualified for a range of designations. There were 95 (60.9%) children with one need, 20 (12.8%) with two needs, and 27 (17.3%) with three or more needs.

The most commonly reported designation was “D: Physical Disabilities or Chronic Health Impairments” ($n=62$, 39.7%), followed by “G: Autism Spectrum Disorder” ($n=45$, 28.8%) and “A: Physically Dependent ($n=38$, 24.4%)” (although only a single/primary designation is received per year, some parents indicated more than one designation).

Impact of COVID-19 on School Attendance

For the 113 students attending ‘brick and mortar’ schools for in-person instruction in the 2019/2020 school year, between March 17 and May 29, 2020:

- 69 (61.1%) did not attend school at all.
- 22 (19.5%) attended school in-person full-time.
- 11 (9.7%) attended school in-person part-time because a full-time in-person option was not offered by the school.
- 2 (1.8%) attended school in-person part-time by choice.

For the 113 students attending ‘brick and mortar’ schools for in-person instruction in the 2019/2020 school year, between June 1, 2020 and the end of the 2019/2020 school year:

- 50 (44.2%) did not in-person because parents chose to keep child at home.
- 12 (10.6%) attended school in-person full-time.
- 21 (18.6%) attended school in-person part-time because a full-time in-person option was not offered by the school.
- 9 (8.0%) attended school in-person part-time by choice.
- 4 (3.5%) did not attend in-person because trained staff were not available to support students’ needs.
- 3 (2.7%) did not attend in-person because their care plan (required for staff training) was not updated.

ⁱ For more information about British Columbia’s Special Education Services, please visit: https://www2.gov.bc.ca/assets/gov/education/administration/kindergarten-to-grade-12/inclusive/special_ed_policy_manual.pdf



Social Services & Impact of COVID-19

During the first wave of COVID-19, the BC Ministry of Children and Family Development introduced a number of initiatives. We asked respondents if they were able to access these initiatives on behalf of their 188 children with medical complexity.

- 72 (38.3%) children's parents accessed flexible use of respite funds (for homemaking like cleaning and meal prep, caregiver relief for siblings).
- 41 (21.8%) accessed additional emergency relief support funding. There were two waves of this funding (March to June and July to September) and each wave was comprised of an additional \$225 per month.
- 29 (15.4%) accessed 35% of Autism Funding usable for equipment, flexible rules around professional signature on justification formⁱ.
- 9 (4.8%) accessed adjustments to policy and practice to ensure continued access to services and supports where possible.
- 7 (3.7%) accessed relaxed rules around access to At Home Program supports.
- 6 (3.2%) accessed Respite/Supported Child Development programming during school hours.
- 3 (1.6%) accessed temporary suspension of maintenance payments.

Notably:

- 73 (38.8%) children's parents were not able to access any of the options above.

ⁱ Typically, one can allocate up to 20% of Autism Funding to assist with the cost of purchasing equipment and supplies, training, or travel to support the child's therapy goals. For more information, please visit: <https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/special-needs/autism-spectrum-disorder/autism-funding/purchase-equipment-supplies>



Profile of Survey Respondents (Parents/Guardians)

156 parents/guardians completed the survey. The average age of respondents was 41.1 years. Most ($n=143$, 91.7%) respondents identified as women. The majority of respondents had completed post-secondary education ($n=120$, 76.9%) and their primary language was English ($n=151$, 96.8%). Most of the respondents were of European descent ($n=112$, 71.8%).

Age (in years) ($n=153$)	
Average	41.1
Range	23 - 71
Gender (#, %)	
Man	9 (5.8%)
Woman	143 (91.7%)
Gender non-conforming	1 (0.6%)
Prefer not to say	2 (1.3%)
Missing	1 (0.6%)
Marital Status (#, %)	
Common-law	16 (10.3%)
Divorced	11 (7.1%)
Married	108 (69.2%)
Separated	8 (5.1%)
Single	12 (7.7%)
Missing	1 (0.6%)
Education (#, %)	
High school diploma	33 (21.2%)
College diploma	51 (32.7%)
Bachelors degree	49 (31.4%)
Masters degree	17 (10.9%)
Doctoral degree	3 (1.9%)
Missing	3 (1.9%)
Primary language (#, %) (categories not mutually exclusive)	
English	151 (96.8%)
American Sign Language (ASL)	2 (1.3%)
Spanish	2 (1.3%)
Other	2 (1.3%)
Ethnicity (#, %)	
Aboriginal (includes First Nations, Inuit, Metis)	9 (5.8%)
European (includes British, Irish, German, Dutch, Ukrainian, Italian, Russian, etc.)	112 (71.8%)



East Asian (includes Chinese, Japanese, Korean, etc.)	2 (1.3%)
South Asian (includes East Indian, Pakistani, Sri Lankan, etc.)	2 (1.3%)
Latin American, South American, Central American	2 (1.3%)
Australian, Pacific Islander	2 (1.3%)
Other	17 (10.9%)
Prefer not to say	9 (5.8%)
Missing	1 (0.6%)

Most of the respondents ($n=144$, 92.3%) indicated that their relationship to their medically complex children was 'mom.' Most of the respondents ($n=131$, 84.0%) had one medically-complex child.

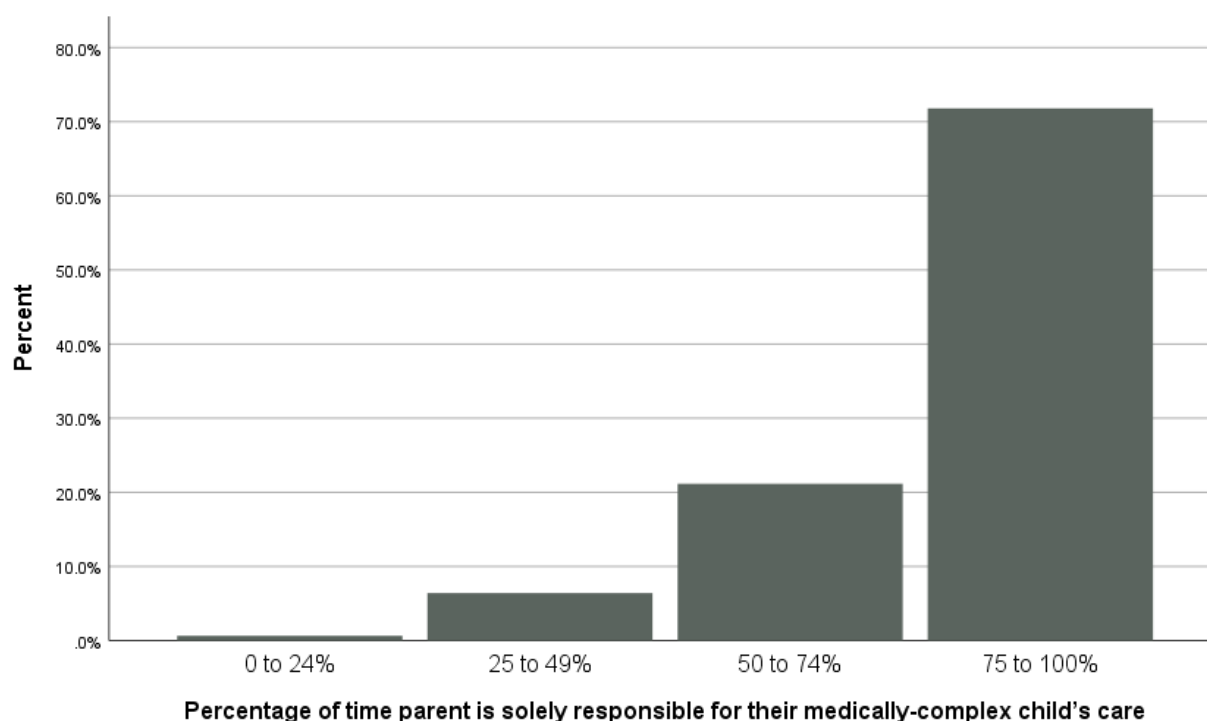
Relationship to medically-complex child(ren)	
Mom	144 (92.3%)
Dad	9 (5.8%)
Foster mother	1 (0.6%)
Grandmother	1 (0.6%)
Missing	1 (0.6%)
Number of medically-complex children	
1	131 (84.0%)
2	19 (12.2%)
3	5 (3.2%)
5	1 (0.6%)
Number of children in household ($n=156$)	
Average	2.2
Range	1-5



Impact of COVID-19 on Parents/Guardians

Respondents were asked to indicate the percentage of time they are solely responsible for the care of their medically complex child(ren).

- Only one (0.6%) respondent indicated that they were responsible less than 25% of the time.
- 10 (6.4%) indicated they are responsible 25% to 49% of the time.
- 33 (21.2%) indicated that they are responsible 50% to 74% of the time.
- 112 (71.8%) indicated that they are solely responsible for their child(ren)'s care 75% to 100% of the time.



Employment (Pre-Pandemic)

Before COVID-19: 47 (30.1%) of respondents were employed full-time. 26 (16.7%) were employed part-time. 22 (14.1%) were self-employed. 38 (24.4%) were not employed. Three (1.9%) were on paid leave (e.g., parental leave). 19 (12.2%) indicated 'other'. One (0.6%) was missing.

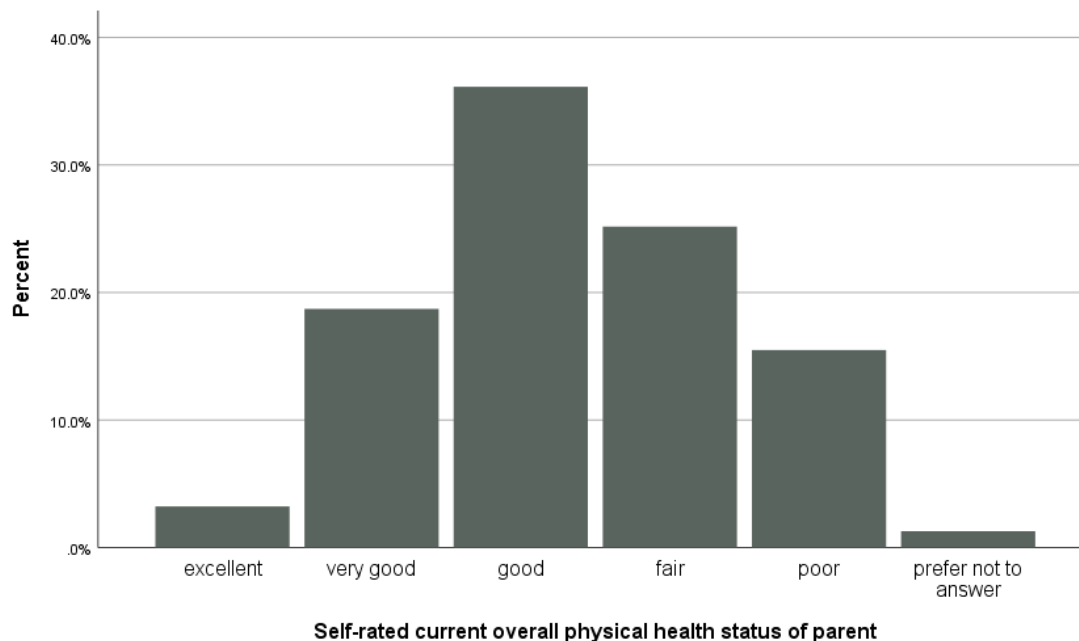
Impact of COVID-19 on Employment

In the first wave of COVID-19, respondents' employment rates fell: 38 (24.4%) were employed full-time, 20 (12.8%) were employed part-time, 16 (10.3%) were self-employed, and 52 (33.3%) were not employed. Eight (5.1%) were on paid leave (e.g., parental leave). 21 (13.5%) indicated 'other'. One (0.6%) was missing.

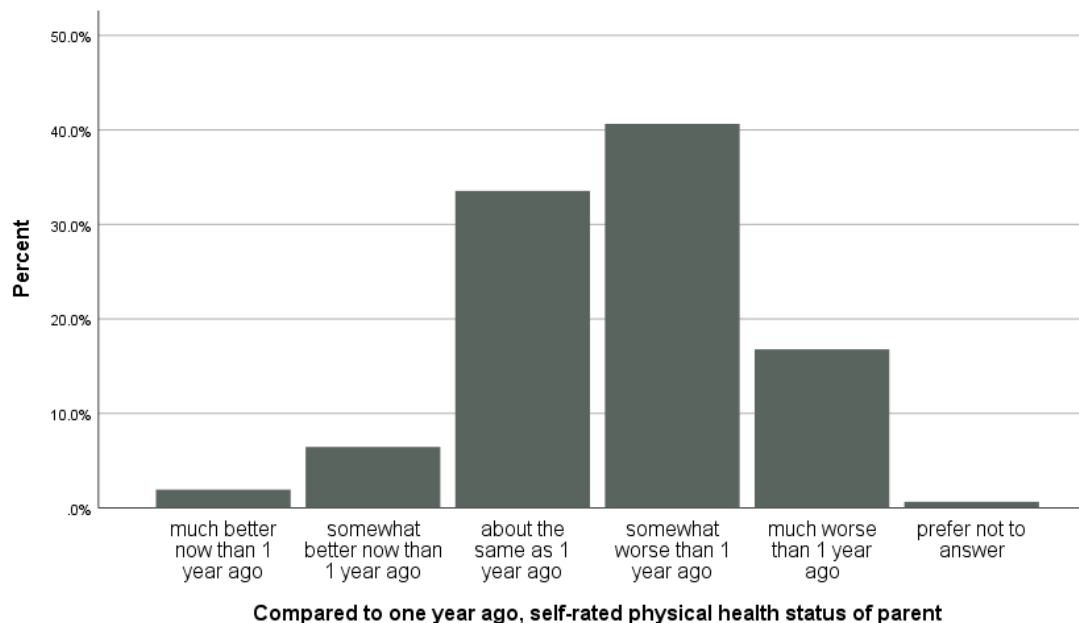


Impact of COVID-19 on Respondents' Health & Well-being

About one-fifth ($n=34$, 21.8%) of respondents rated their **current overall physical health status** as 'excellent' or 'very good.' Over one-third ($n=56$, 35.9%) rated their overall physical health status as 'good' and 40.4% ($n=63$) rated their overall physical health status as 'fair' or 'poor.'

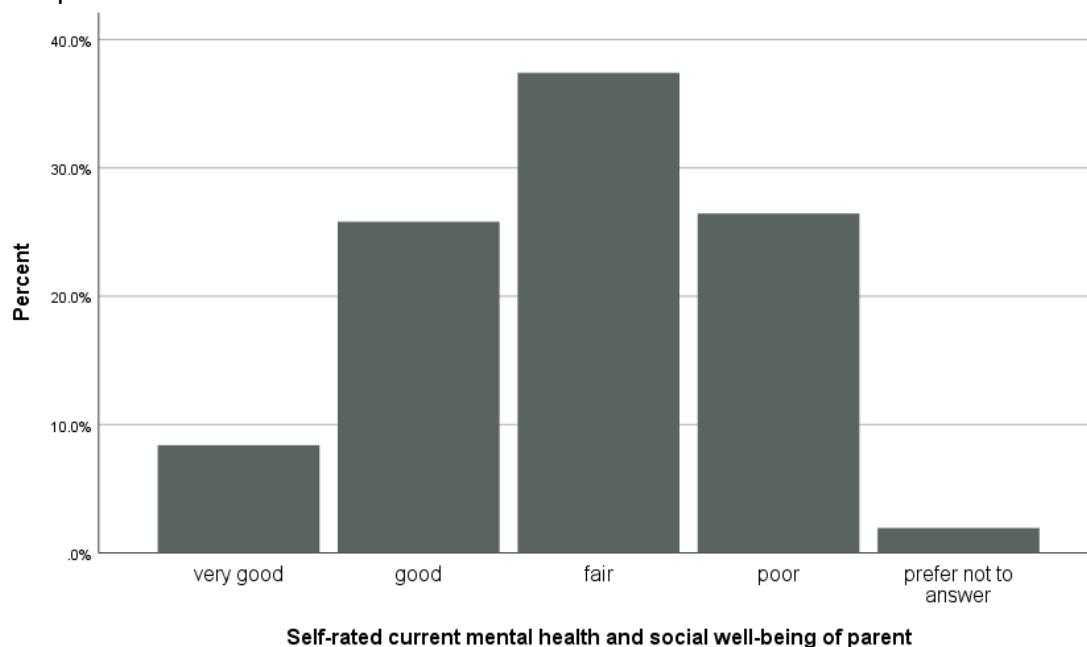


When asked to **compare their physical health status to one year ago**, only 13 (8.3%) report that their physical health status is now 'much' or 'somewhat' better. One-third ($n=52$, 33.3%) report that their physical health status is about the same. The majority of respondents ($n=89$, 57.1%) report that their physical health status is 'somewhat' or 'much' worse than one year ago.

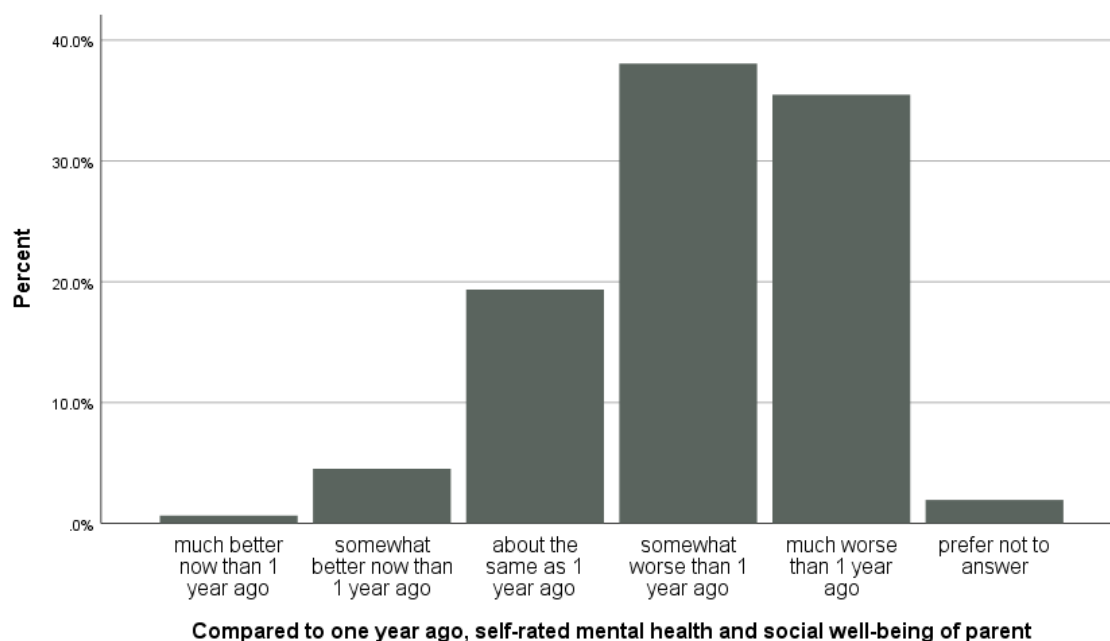




About one-third ($n=53$, 33.9%) of respondents rated their **current mental health and social well-being** as 'very good' or 'good' (note: no one rated this area as 'excellent'). Over one-third ($n=58$, 37.2%) rated their mental health and social well-being as 'fair' and 26.3% ($n=41$) rated it as 'poor.'



When asked to **compare their mental health and social well-being to one year ago**, only eight (5.1%) report that their mental health and social well-being are now 'much' or 'somewhat' better. Almost one-fifth ($n=30$, 19.2%) report that their mental health and social well-being 'about is the same'. The majority of respondents ($n=114$, 73.1%) report that their mental health and social well-being is 'somewhat' or 'much' worse than one year ago.





Profile of Family and Community & Impact of COVID-19

Almost three-quarters (73.1%) of the respondents were part of a dual-parent family, 15.4% were single parents, and 8.3% were co-parenting. Most (78.2%) of the respondents live in a house and over two-thirds (69.2%) own their homes.

Family arrangement (#, %)	
Co-parenting	13 (8.3%)
Dual parenting	114 (73.1%)
Single parent	24 (15.4%)
Other	5 (3.2%)
# of people living in household (n=156)	
Average	2.4
Range	1 - 11
Type of dwelling (#, %)	
Apartment/Condo	11 (7.1%)
House	122 (78.2%)
Townhouse	17 (10.9%)
Other	6 (3.8%)
Dwelling status (ownership) (#, %)	
Own home	108 (69.2%)
Rent home	43 (27.6%)
Other	5 (3.2%)

Geographic Location

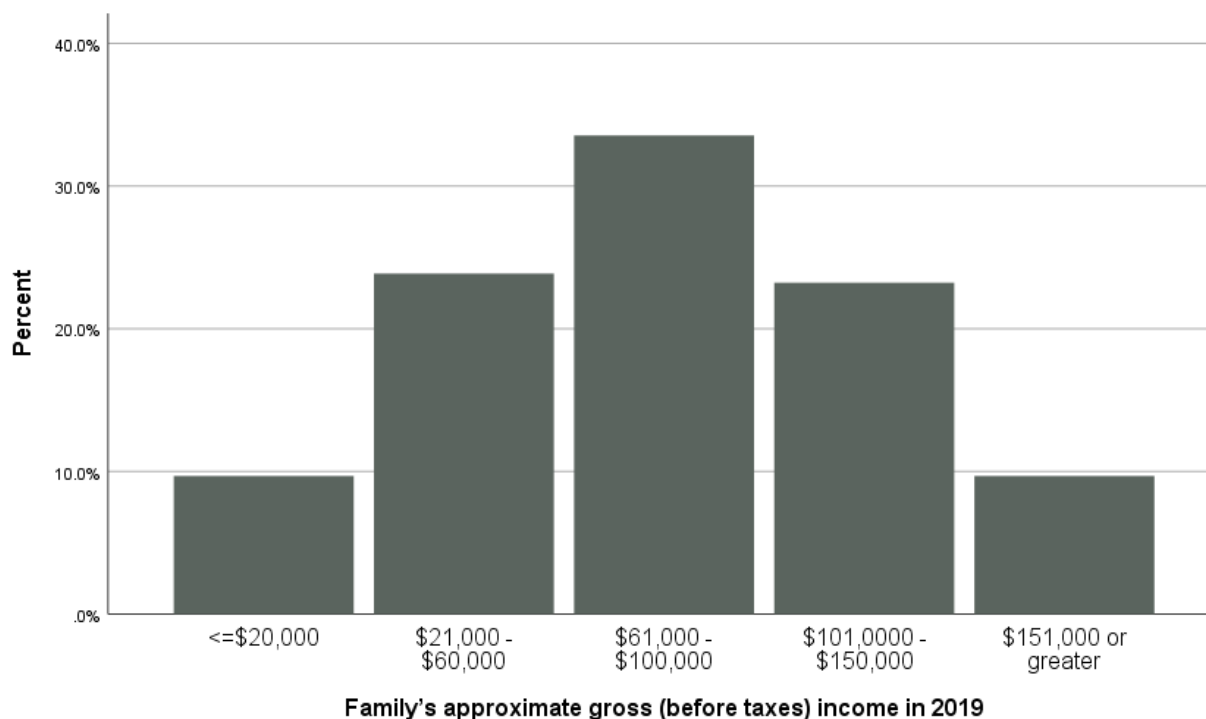
The majority of parent respondents ($n=69$, 44.2%) resided in the Fraser Health Authority, with smaller representation in the other regional health authorities: Interior Health ($n=25$, 16.0%), Island Health ($n=28$, 17.9%), Northern Health ($n=16$, 10.3%), and Vancouver Coastal Health ($n=16$, 10.3%).

In terms of the population size where they reside, 35.9% ($n=56$) of respondents resided in large urban areas, 39.7% ($n=62$) resided in medium-sized communities, and 24.4% ($n=38$) reside in rural or small communities.



Household Income (Pre-Pandemic)

In 2019, 15 (9.6%) of the respondents' households had an annual gross income of \leq \$20,000 and an equal number (9.6%) had annual gross incomes of \$151,000 or greater. Almost one-quarter ($n=37$, 23.7%) had incomes of \$21,000 to \$60,000, one-third ($n=52$, 33.3%) had incomes of \$61,000 to \$100,000 and 23.1% ($n=36$) had incomes between \$101,000 and \$150,000.



Impact of COVID-19 on Household Income

In the first wave of COVID-19, almost half ($n=76$, 48.7%) of the respondents experienced a decrease in their household income.

Decreased	76 (48.7%)
Remained the same	63 (40.4%)
Increased	16 (10.3%)
Missing	1 (0.6%)

57 (36.5%) respondents accessed the Canadian Emergency Response Benefit, and 16 (10.3%) accessed Employment Insurance. Just over half of the respondents ($n=84$, 53.8%) had not accessed formal financial supports.



Food Security (Pre-Pandemic)

Prior to COVID-19, 141 (90.4%) of respondents reported they did not access any type of food security program.

Of the 15 parents who did access food security programs:

- 3 (20.0%) accessed both formal (e.g. Food Bank) and informal (e.g. Church/Religious community) supports.
- 6 (40.0%) accessed formal supports only.
- 6 (40.0%) accessed informal supports only.

Impact of COVID-19 on Food Security

Since the first wave of COVID-19, the number of respondents reporting they did **not** access food security programs fell to 130 (83.3%).

Of 26 parents who did access food security programs:

- 4 (15.4%) accessed both types
- 7 (26.9%) accessed formal supports.
- 15 (57.7%) accessed informal supports.



Conclusions

COVID-19 and associated pandemic restrictions have had wide-ranging – mainly negative -- consequences for medically complex children and their families.

These consequences are particularly obvious in relation to access to healthcare services (including medical specialist and therapy services), education, and social services. There are significant negative impacts on parental physical and mental health, as well as on family income. Policies that focus on ensuring access to services and shifting funding directly to families are urgently needed as we enter the ‘second wave’ of the pandemic.

There is also an important role for research to continue to document and illuminate the complexities of these families’ pandemic experiences. We anticipate that there will be long-term implications for children in relation to restricted access to healthcare and therapy services, as well as education. We also need to investigate different experiences based on factors, such as family income, housing stability, and geographic location, which can further contribute to vulnerability and marginalization.



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Survey Respondents

We are very grateful to respondents for taking time in their busy lives to complete the survey.

Research Team & Community Partners

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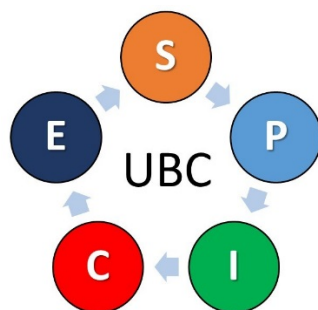
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