

## Major Challenges for Parents of Children with Medical Complexities

*This document outlines the major challenges parents experience when caring for their child with medical complexities.*

### PERSONAL HEALTH – EMOTIONAL AND PHYSICAL



- Parents experience grief, anxiety, depression, and Post Traumatic Stress Disorder related to providing care for their child/children with medical complexities.
- Parents are frequently exposed to triggers that bring back memories of trauma related to past medical interventions, medical decline, and care needs for their child.
- Parents experience exhaustion because they are required to be hyper-vigilant with their child and are often sleep deprived.
- There is a lack of awareness, sensitivity and compassion towards parents who experience mental health challenges due to the trauma their child has experienced.
- Community based therapeutic supports have long waitlists, and the costs associated to fee for service support are out of reach financially for most families.
- Therapeutic supports are not always accessible due to challenges related to arranging for respite.
- Parents have difficulty in recruiting qualified personnel with experience in working with families with children with medical complexities. This results in minimal time for parents to focus on self-care.
- Parents are experiencing chronic health issues as a result of being in a caregiver role 24 hours a day.
- Accessing physical support therapies such as massage therapy, physiotherapy, or other self-care supports can be challenging due to lack of time and respite, and the cost associated.

### ISOLATION



- The role of a caregiver is all consuming. Parents speak of not being able to turn off 'caregiver' role and are uncomfortable stepping out of role that they are very familiar with. There are few formal mechanisms to connect families of medically complex children with one another.
- Families are increasingly isolated during peak illness times (4 months of the year) because it is unsafe to see others due to the risk of catching something.
- Support groups are often diagnosis based. Families with medically complex children are often without a diagnosis, or have multiple diagnoses making it challenging to find a support group that fits their situation.
- Challenges with respite hinder the opportunity for families to connect in person with others.
- Parents feel they can no longer relate to social networks that were established prior to having a child/children with medical complexities.

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### FINANCIAL



- Parents incur significant out of pocket expenses on equipment, therapies, transportation, special diet, respite, etc. This also includes the cost of parking and gas for the various hospital visits and appointments.
- Parents are responsible for navigating the complex web of federal, provincial and municipal supports in order to receive financial assistance for their child's medical needs.
- Parents must complete multiple applications since the funding supports operate independently of one another and application processes aren't streamlined.
- Once the applications are approved, parents spend an onerous amount of time to complete the accounting that supports the funding claims.
- Parents are required to pay out of pocket and then submit a claim for reimbursement for certain financial supports. Lengthy waits to receive the return can discourage families from making decisions related to care.
- Families who earn over approximately \$65,000 per year do not qualify for any financial assistance for their child's medical needs. There is little flexibility or consideration for families on this salary who have multiple children.
- Parents experience an onerous process for filing taxes because of the extent of their medical expense claims as well as long wait for reimbursement.

### RESPIRE – PAID CARE SUPPORT



- Parents of children with medical complexities have difficulty recruiting qualified personnel with experience. Respite worker databanks are not specific to children who are medically complex. There are only a limited number of workers who are qualified and have experience with the medically fragile and technology dependent population.
- Working with children with medical complexity requires specialized training such as nursing; therefore respite services are more costly.
- There is a high turn-over rate for Nurses, as well Personal Support Workers (PSWs) due to the entry level nature of the position. This makes it hard to retain consistent support.
- Training workers requires lots of investment because of all of the unique needs inherent to medically complex children (equipment, medication, record keeping, emergency protocols, etc.)
- Parents have difficulty trusting someone else to provide consistent and vigilant care for their child.
- Out of home respite facilities are unable to provide 1 on 1 support for 24hrs a day.

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## DAYCARE – CHILDCARE



- Daycares are reluctant to accept a medically complex child because they become responsible for initiating requests for additional supports such as enhanced staffing and training to accommodate that child.
- When there is a daycare subsidy freeze, there is no funding available for additional supports and training. When this happens, children with medical complexities cannot attend.
- Existing programs specific to medically complex children do not operate at full time hours. This prevents the primary caregiver from participating in full-time employment or education.
- Parents are unable to afford daycare for any of their children because of the high cost of caring for a child with medical complexities. This may result in the primary caregiver staying home with their children.

## SCHOOL



- Nursing support in the school is not always reliable or consistent. Parents have to be available to attend to their child's needs at school, or keep the child home in order to receive the required care.
- There is designated support for children transitioning into school through the Children's Treatment Centre. This is specific to children with a physical disability that includes a motor deficit. Children who do not fall into this category do not receive any transition support.
- Parents have to continuously advocate for their children as they face additional barriers and challenges in the school environment. Challenges include:
  - A. Children with medical complexities who are in the mainstream school system are often placed in age specific classrooms as opposed to developmentally appropriate classrooms.
  - B. Children with medical complexities experience bullying and isolation from peers.

## RECREATION



- There is a lack of accessible and inclusive activities and summer programs. Parents must make alternate arrangements during March break, summer break, and other holidays as recreational activities are not an option.
- Parents are looking for the space to connect through activity with their child/children outside of their caregiver role. Finances are often a barrier to making this happen.
- Parents have a desire to see inclusive programming that is available to both medically complex children and children with no medical complexities.

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## EMPLOYMENT



- The primary caregiver is often unable to work because of the level of commitment to care and the unpredictability of the child's needs. This includes numerous appointments and unplanned admissions.
- There are numerous barriers which need to be addressed before a parent is even able to consider employment (see funding and finances, respite, daycare, and school )
- Parents looking for employment have difficulty finding a flexible employer or are reluctant to tell an employer of the unpredictability of their child's care needs.
- For those parents who are employed, there is an ongoing need to advocate for increased awareness and understanding with employer.

## FAMILY



- The care needs of medically complex children place strain on marital health, potentially leading to breakdown in marriage.
- Children may experience mental health challenges related to having a medically complex sibling.
- Families are unable to access pro-social activities or mental health supports because of financial and accessibility barriers and time constraints.
- The care needs of medically complex children are so great that it doesn't leave much room for parents to just be parents.

## HOUSING



- Parents experience challenges in securing affordable housing that will also meet the child's accessibility needs.
- There are high costs to modify a home for a medically complex child and funding is not always available.
- Parents experience challenges when living in a rental unit. Maintenance is not up to date and healthy living conditions are not adequate for the child's medical needs. Parents have limited ability to modify the unit for accessibility.
- There are lengthy waitlists for subsidized housing. Even more so for an accessible unit.

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### TRANSPORTATION



- Parents incur significant expenses related to transportation for the following reasons:
  - A. They must rely on taxis if they do not have access to a car. The bus is not always a safe option for many children.
  - B. Parents often have to purchase a vehicle/different vehicle in order to accommodate equipment and accessibility needs.
  - C. There are high costs associated with adapting a vehicle. These costs are not always covered.
- Many children require two adults to transport them for safety reasons in the event of medical complications. Most respite workers are not able to accompany the child in the car therefore, parents must make alternate arrangements for transportation.