March 2019

Recommendations

From: BC Parents of Complex Kids (A group of 300 families with children receiving funding from the At Home Program)
To: BC Ministry of Family and Children (MCFD)
Children and Youth with Special Needs (CYSN) Service Framework Team

At Home Program
BC Parents of Complex Kids

Contents

We would like to take this opportunity to thank the At Home Program representatives for opening an avenue of participation in this process of research. With enthusiasm, we welcome the creation of the Children and Youth with Special Needs Service Framework. A baseline upon which to build improvements that we hope will bring greater consistency, effectiveness, and efficiency to the quality of services offered and delivered through the AHP.

Recognizing that our children are the target population of the AHP, we believe we possess invaluable knowledge and expertise with regards to this program. We are willing to share our experience as users and take part in this collaborative effort to uncover the successes and challenges of the AHP. We endeavor to help identify where services fall short for our children and the resulting opportunities for improvement.

We acknowledge that the population of children and families served by the AHP is highly diverse in its composition. Its heterogeneity ranges from the varied health complexities and needs of each child and family, through to the very different socioeconomic status and cultural origins represented. Despite this great diversity, the most urgent needs and challenges that our children and families are facing can be summarized in certain priorities that require special attention. This document is meant to summarize the issues that represent the greatest challenges to our children and families, and which we believe should be prioritized in the process of creating a baseline upon which to build improvements to the program.

It is important to highlight that the following recommendations are a result of extensive and ongoing work over the past two years. It has been the collaborative effort of close to 300 At Home Program families, connecting through social networks and various other means of participation. We share common challenges and experiences arising from the care of our complex children as we navigate the current system of support. Our group has become an important sphere of family support and knowledge, allowing parents to connect and exchange information in a consistent and effective way.

Also, it is important to note that we have carefully reviewed the recent report from the Representative for Children and Youth in BC titled Alone and Afraid, and deeply appreciate its insights and contributions. The details of this child and families' situation were alarming but unfortunately not completely surprising. The strongest and most resilient of us have immense struggles. We are deeply concerned that there are more extremely vulnerable families that access the At Home Program and are at great risk of falling through the cracks. Therefore, we support the various suggestions and specific recommendations outlined in that report.

We have managed to pinpoint several critical areas that will be summarized in a series of recommendations and suggestions throughout this document. We would like to draw attention to the fact that there is a broad range of issues that are not mentioned in this document but are still of great concern for many families.

We thank you in advance for listening to our collective voices and considering our suggestions. This report is the result of a long process in which all families have invested valuable time to provide input. We would also like to take this opportunity to express our desire to participate actively as a group in the current research process as MCFD moves towards the creation of the Children and Youth with Special Needs Service Framework.

A Brief Introduction to Our Reality

Families of children with severe disability and complex health care needs struggle to overcome a broad range of problems and difficulties. We face daily challenges that are not easily understood by government agencies, health professionals and society as a whole. We strive to care for our complex children and provide them with opportunities to reach their potential, while also meeting the rest of our family's needs.

A great deal of our time and energy is spent on the personal care routines of our complex child. Lifting, bathing, toileting, feeding, changing, attending medical appointments and therapy sessions, following treatments, driving back and forth, as well as navigating the system to access the services they require. This frequently leaves us feeling physically and mentally exhausted.

Some of us also struggle financially as our employment and economic situation is under heavy pressure. Many families are single income earners or are under-employed due to the difficulty of providing 24/7 care for our children. We are unpaid caregivers of medically complex children and we are invariably caught in a downward spiral of greater economic needs and lower earning power.

In addition to the financial hardship, we also need to cope with the lack of time for leisure and social interaction. Meeting the daily needs of our medically complex children is extremely time consuming and emotionally challenging. These pressures increase the level of psychological stress for both parents and siblings. Ultimately, it impacts our ability to properly care for our children and families.

Depression, anxiety and isolation are common symptoms of our family situations. We feel the negative impacts this has on our emotional and physical wellbeing but we are so drained by our parenting obligations, that seeking professional help for our mental health challenges can be difficult and costly.

A Look into the Current System of Support

Although it can be very challenging for families, we are aware of the benefits of caring for our complex children “At Home” when possible. Like all parents, we value our capacity to provide care for our children and give them the opportunity to fulfill their potentials. We have developed strength and resilience, as well as high levels of patience and perseverance in the process of caring for our complex children.

We praise the efforts made by MCFD in the last few decades to provide support and services in the community and celebrate the opportunity for our children to live with our families or in alternative family care. We recognize that since its creation in 1989, the At Home Program has given thousands of children the opportunity to grow up with the support and love of their families and become active members of their communities. We very much appreciate the services MCFD currently provides and recognize that without these services, our daily struggles to meet our children’s needs would be exacerbated.

We believe that the current state of under-funding of the AHP, as well as the lack of periodic evaluations to reassess the needs of its target population, have undermined its ability to provide enough appropriate and responsive support to our children and families. The program has seen very minimal funding increases since its inception and this has lead to a slow but steady erosion of what was a very robust program when it was created.

Families are reaching capacity as they strive to cover extraordinary expenses including (but not limited to) therapies, positioning and mobility equipment, orthotics, communication equipment, caregiving/respite services, home adaptations and accessible vehicles. Many of these expenses were covered completely when the program was created but a lack of reassessment has allowed the program to deteriorate over the past 30 years and inflation has dramatically affected the cost of products and services. We hope that in the process of creating this framework, MCFD will be able to identify the gaps, increase funding substantially and address the needs of our children and families.

We cannot help but compare the services provided by Autism Funding and the At Home Program, as they are both the jurisdiction of CYSN and MCFD. Evidence shows there are a great number of asymmetries that have created large inequities and differentiated access to the services and supports offered. It is clear that Autism Funding is provided as a support for children’s development and inclusion while the At Home Program does not have a mandate to support our children’s development and inclusion in society. In fact, the AHP is struggling to meet the basic mandate of providing medical necessities. Policies are required to correct these inequalities and guarantee equal opportunities for all children, regardless of their disability.

As primary users of the program, we would like to pinpoint several shortcomings and deficiencies that we have identified. As mentioned earlier in this document, these issues are considered to be priorities by the majority of our families, and we hope they can be addressed through this evaluation process, so that we can access the quality, inclusive supports and services that our children and families need and deserve.

Family Caregiver Pay and Respite Benefits

It is widely recognized that caring for a family member with a severe disability or complex health care needs is one of the most challenging jobs there is. Some of our families have access to Nursing Support Services, but many of us do not receive any type of caregiving support, even though we are providing 24/7 care for severely disabled individuals and our ability to be employed elsewhere is often diminished. As unpaid caregivers, we believe it is exceptionally important to standardize approaches to assessing caregiving situations and developing programs to support caregivers based on a consistent set of values and principles.

While recently, increases in payments have been announced for foster parents, adoptive parents and relatives caring for children in BC, payments to parents caring for severely disabled and medically complex children have not even been contemplated. The absence of appropriate support is putting parents in a situation of social and physical risk, hindering our ability to sustain our role as caregivers and threatening our family's stability in the foreseeable future. As unpaid caregivers, we represent a vulnerable population, not appropriately recognized and respected for our contributions. There is not only a lack of mechanisms directed at safeguarding our physical and mental health but also a lack of policies and programs to address our immediate needs and problems.

In addition to Family Caregiver Pay, one of the most urgent matters to tackle is the lack of sufficient Respite Benefits. Respite is exceptionally important to prevent caregiver burnout and helps primary caregivers manage their emotional stress and physical strain. It is well known that having access to sufficient quality respite benefits is fundamental for keeping medically complex children safe at home, as well as providing all family members with a better quality of life.

Despite this, accessing Respite Benefits is a difficult journey in the current system of support. Most families are first placed on a long wait list and when they finally get to the top of the list, they find that the monthly base amount of $233 is insufficient to cover their urgent needs, as it only represents an average of 2.5 hours per week of respite care. Families next struggle is to find respite workers willing to commit to only work 2.5 hours a week. There are also some circumstances where families are made to choose between Respite Benefits and Medical Benefits and so are left with unmet needs in one area.

It is important to note that the basic amount of respite funding of up to $2,800 provided annually to each family has not increased since the program was developed in 1989 and lengthy waitlists persist. Families today receive fewer hours of respite because the cost of hiring respite workers has increased substantially while the funding has remained steady[1].

Therapies and Early Intervention Programs

As Article 26 of the Convention on the Rights of Persons with Disability (CRPD) mentions, our children have the right to access comprehensive habilitation and rehabilitation services and programs. Effective, appropriate and continual therapies are of crucial importance to the development of our children. They are essential to improve their health and obtain a maximum level of independence, inclusion, and participation in all aspects of life.

Currently, the AHP covers an average of four sessions a month of Occupational Therapy, Physiotherapy, and Speech Language Pathology through School-Aged Extended Therapies. However the maximum hourly billing rate of $80 per hour is unreasonable as private therapists charge a minimum of $100 per hour. Families are forced to top up the hourly rates, expending a monthly average of $240 or more in order to pay for weekly therapies. For some families, this is a barrier to their child receiving any therapy at all or it can potentially reduce the amount of therapy they can afford.

Another barrier is that families are not permitted to pool therapy funding and allocate it as needed to Occupational Therapy, Physiotherapy and Speech Language Pathology. For example, some of our children will certainly benefit more from an additional session of Physiotherapy and do not need as much help from a Speech Language Pathologist but the program is not flexible to allow for individualized care where parents can allocate the funding where it will be most beneficial for their children.

There are also various types of therapies that fall outside of these three options including behavior intervention, music therapy, therapeutic horseback riding, conductive education, ABM (Anat Baniel Method), NDT (Neuro Developmental Treatment) and aquatic therapy. Many children have experienced great benefits from these types of therapy but families need to pay out of pocket as they are not on the list of approved therapies.

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[1] Representative for Children and Youth, *Alone and Afraid. Lessons learned from the ordeal of a child with special needs and his family*, Victoria, B.C., 2018, p. 67.

The crisis in Early Intervention Programs is also a very urgent matter to address. Early Intervention lays a foundation that will improve the lives of children with disability and offer greater opportunities for their development. Early Intervention is not only a basic human right of children with disability as mentioned in the Convention on the Rights of Children (CRC) and the CRPD, but plays an important role in improving the outcomes for children, as well as reducing the long-term cost to government of supporting children and youth with severe disability (ibid, p. 66).

Currently, the majority of contractors hired by MCFD to deliver the regional Early Intervention Programs are offering therapy sessions only once or twice a **month**, while the most successful Early Intervention Programs around the world, recommend at least 3 therapy sessions a **week** in order to obtain positive outcomes. Early Intervention Programs are under-funded and limited in their capacity. They lack staff, resources, and proper plans and programs to accommodate our complex children.

Two decades ago, children under five in Early Intervention Programs had therapy sessions at least once or twice a week. Today, parents are reporting having therapies as little as once every six weeks. Another challenge with the Early Intervention Programs is that the therapists are often well versed in dealing with children that have mild developmental or physical challenges, but are not always well versed in dealing with our complex children. Sometimes private therapy is the only way to find therapists that specialize in the needs of our complex kids.

Another concern with regards to School-Aged Extended Therapies Early and Intervention Programs is that the barriers we face in this funding category do not exist for children who receive Autism Funding from MCFD. Autism Funding does not dictate a maximum hourly billing rate for therapies. Part of the reason we are told that these rate caps exist is to protect families from high rates charged by therapists. Unfortunately this is not working at all because in our communities, AHP kids are seeing the same private therapists that see kids with Autism Funding.

Also, in the Autism Funding program, families are able to choose the most beneficial and appropriate therapies for their children and have access to private funding for therapy in the early years (before age 5). Autism Funding recognizes the huge benefit of early intervention and provides direct funding for private therapy so that children under the age of five have access to enough therapy and also continue receive services through the Early Intervention Program if they wish.

Medical Equipment

As Article 20 of the CRPD mentions, persons with disabilities have the right to access quality mobility aids, devices and assistive technologies. Special medical equipment known as positioning and mobility devices, not only improve our children's health and quality of life but allows them to participate more fully in society.

The cost of this equipment has significantly increased in the last couple of decades while the funding provided by the AHP for this equipment has remained steady. Our families are continuously “topping up” or finding charity support in order to acquire the basic medically necessary equipment.

The AHP funding category “Alternate Positioning Devices” has a funding cap of $3200 that was set in 1989. At that time it was possible to purchase a walker, standing frame and ‘comfy’ chair for less than $3200. The amount of $3200 does not go far today and often only covers 50% of the cost of a walker or standing frame. Many of our children need 24/7 postural support and some are at high risk of developing scoliosis or kyphosis of their backs as well as hip displacement. Alternative positioning devices are not only particularly import to prevent injury but to promote healthy growth and development of the skeletal and muscular system, and postponement or avoidance of serious surgeries.

This leaves families looking to charities or paying out of pocket for the remaining balance. As well as the other pieces of medically necessary equipment their child needs that also fall under this funding category. These costs can be crippling for families and continue to add up over the years as their children grow and need new equipment. Some families find help through charity organizations but many do not qualify as their income exceeds the income thresholds set by most nonprofits. These thresholds do not always consider the cost of living, family composition and the extraordinary financial needs of some complex children and their families. In the end, some children go without the basic medically necessary equipment required to improve their health and quality of life.

Another problem families are currently facing is an increase in the cost of orthotic devices. Orthotic devices are an essential part of treatment for many children as they help to establish more normal conditions of joint motion and muscle function, providing a stable base of support, reducing the impact of spasticity on upper and lower limbs and controlling muscular imbalance. This can help a child develop a higher level of functioning and prevent medical interventions.

In the past year, BC orthotics providers have been starting to raise the cost of their products and services due to inflation. There has not been an increase to the funding maximums for orthotics in approximately ten years. These increased costs can amount to thousands of dollars and families are now paying out of pocket for orthotics that historically, were a fully funded benefit.

Medical Supplies

The AHP provides a variety of medical supplies for families with medically complex children. Many of these supplies are crucial in the daily care, health and life support of our children. We need to be able to trust that we will receive adequate and appropriate supplies in a timely manner from the AHP. Families are often left scrambling when they receive no notification that their child's specialized feeding formula or other critical products, will not be arriving at their door when they are expected. A better system of communication would bring many benefits to both families and the AHP, and allow for information sharing regarding back orders, new product requests and other important correspondence. Families also want to see the removal of quantity limits on medical supplies so that they do not need to reuse "single use" supplies and can further protect their children's health.

Biomedical Equipment

Biomedical equipment is vital and sustains life in many instances. Families urgently need access to a 24/7 provider that can deliver back up equipment within hours so that they do not need to admit a medically fragile child to a hospital unnecessarily. Currently, this is often the only option when a piece of vital equipment malfunctions or breaks. For families that live in rural and hard to access locations, it may be necessary to provide funding for back up equipment.

Alternative and Augmentative Communication Equipment

Likewise, as Article 26 of the CRPD mentions, our children have the right to access and use appropriate alternative modes, means and formats of communication. Alternative and Augmentative Communication (AAC) equipment is particularly important for our non-verbal children. These devices can be used to help non-verbal children communicate their wants, needs, and thoughts by using different types of strategies, including gestures, eye gaze and other strategies.

Access to AAC equipment vastly enhances our children's quality of life and can help them achieve the fullest possible social integration and individual development. Not having access to these technologies hinders our children's ability to express their needs, acquire knowledge and fully participate in society. Currently there is no funding available until children reach school age when SET BC begins to assess children's needs in this area. Even then, funding is limited and it can be years before the appropriate AAC supports are in place. Access to appropriate AAC technologies in the early years is vital for children's development and lays the foundation for later opportunities.

We note that many children with Autism Funding also require AAC equipment. Autism Funding does not have a particular funding category for this equipment but it is flexible to allow for the purchase of computers, laptops and other equipment as decided by the family and justified by a professional.

Accessibility and Safety

Accessible vehicles and home adaptations allow children in wheelchairs and their families to participate in society in a dignified and safe way. The lack of funding in this area of need creates a financial burden and puts children and families at great risk of injury and isolation. Back in 2011, our community welcomed with enthusiasm the creation of the Giving in Action Fund that directly assisted families in need of accessible vehicles and home adaptations. This fund was the result of a joint effort between MCFD and the Vancouver Foundation. Families were able to apply for one-time capital grants to purchase accessible vehicles or make home adaptations.

At the time the importance of this initiative was recognized by MCFD. Children and youth with disability could gain better access to their schools, homes and communities. A few years after the Giving In Action Fund was created, the resources were exhausted and the fund was shut down. Numerous children benefitted from this important initiative but now families have been left without any avenue to access these important resources.

Likewise, some of our families are finding it extremely difficult to secure accessible housing in the rental market. The housing crisis and the general lack of accessible housing units are putting children and caregivers at risk of injury and isolation. BC Housing programs for accessible housing have very long wait lists, and families that do not meet the income or residency requirements are left without options.

Family Supports and Communication Mechanisms

Effective communication between the AHP and our families is essential for the effective delivery of services by the program. The lack of updated communication mechanisms undermines the ability of the program to reach its target population in an inclusive way. We find the system difficult to access and limited in its capacity to provide timely information on the services and products available. Establishing a communication mechanism like the Autism

Funding Unit Portal will allow families to navigate the system in a more consistent and effective way, and will facilitate the exchange of information between the programs and its users.

As recommended in the recent RCYBC report, we strongly support the addition of a case coordinator and a cross ministry integrated service delivery model that would help families navigate and access all necessary services. In the current system this can be complicated and challenging with numerous barriers for all families but especially for our most vulnerable families. Working across ministries would ensure children and families are supported adequately in health, in our schools and at home.

As previously mentioned in this document, depression, anxiety and isolation are common symptoms of our family situations. We feel the negative impacts this has on our emotional and physical wellbeing but we are so drained by our parenting obligations, that seeking professional help for our mental health challenges can be difficult and costly. Providing access to funded family counseling would remove one barrier to access and would acknowledge the unique and challenging circumstances of our families. We note that Autism Funding has a flexible element that allows for family counseling as a funded benefit.

As caregivers, we possess an invaluable understanding of our children's needs, as well as a unique perspective on the functioning of the At Home Program. As key stakeholders, our voices need to be "at the table" to bring greater consistency, effectiveness, and efficiency to the quality of services delivered through the AHP. Establishing a permanent and independent participatory mechanism, such as the AHP Parent Engagement Group, would be a great step towards a more family centered model of service delivery.

Conclusions

As mentioned earlier, the population of children and families served by the AHP is highly diverse in its composition. Its heterogeneity ranges from the varied health complexities and needs of each child and family, to the very different socioeconomic status and cultural backgrounds. We recognize there are a percentage of families whose needs are being met but we believe it to be a small number. These are the children who just meet the eligibility criteria and whose needs are on the less complex end of the scale. On either end of that, we have children who get no funding because they narrowly miss meeting the criteria and then a whole range of needs that extends to the most complex in the province. In the current system, the more complex a child's needs are, the less of those needs are being met.

This discrepancy should come as no surprise since every child and family are different. Because of this, we are strongly convinced that a system that works effectively for all of our families, will have to be based on a more flexible structure in where programs and services are design and delivered using a family-centered approach. This will not only bring more consistency and efficiency to the quality of services offered but will provide more inclusive, responsive and individualized services.

A potential solution in the long term would be to provide a system of individualized supports where the funding meets each individual child's specific needs and funding is provided through collaboration between families and all of the professional supports in the child's life. This model is used in other provinces and so could be examined for effectiveness. In the short term, the current model should expand funding to once again provide a robust program of support that will meet the needs of the most complex child in the province and leave some room for inflation and a plan for periodic reviews.

Recommendations

1. Family Caregiver Pay and Respite Benefits
Recalling Article 28: Adequate standard of living and social protection of the CRPD. *Emphasizing* the fact that the current system of "at home" caregiving could not function without the countless hours of care and resources provided by family members. *Recognizing* that most are single income families and many frequently report financial hardship due to caregiving responsibilities and the inability to work or maintain stable jobs. *Taking into consideration* the importance of valuing the economic and social contributions of caregivers from a rights-based approach and looking into protecting their human rights. *Alarmed* by the higher levels of stress experienced by parents of children with disabilities because of the challenges that arise from providing 24/7 care for children with severe disability and complex health care needs. *Acknowledging* that adequate Respite Benefits are particularly important to prevent caregiver burnout and help them manage their emotional stress and physical strain. Recognizing that families with Autism Funding have the flexibility to access family counseling with their funding. *Taking into consideration* that having access to enough Respite Benefits is fundamental for keeping children with disabilities at home and providing families a better quality of life.

Noting with deep concern that the current base amount for Respite Benefits is definitely insufficient and does not allow caregivers to access the much-needed support they deserve.

Considering that as children grow older, the physical strain in caregivers increases too, Respite Benefits should not decrease when children turn thirteen.

Acknowledging that some families need to choose between Respite Benefits and Medical Benefits.

‘BC Parents of Complex Kids’ **recommends** that MCFD:

- Considers establishing a system of family caregiver pay to help families experiencing financial hardship due to their inability to work.
- Takes into consideration the Caregiver Legislation and Policies recommendations on balancing work and caregiving responsibilities for parents providing 24/7 care for their children.
- Increases Respite Benefits so that caregivers have access to permanent and effective support to alleviate the emotional stress and physical strain that arises from providing 24/7 care for their children.
- Removes the policy that decreases Respite Benefits for children over thirteen considering that as children grow their support needs do not necessarily decrease.
- Expands the flexibility of the use of Respite Benefits to allow caregivers to use the funds for the most effective service.
- Removes the need for some families to choose between Respite Benefits or Medical Benefits and instead meets the actual needs of children and families.
- Removes income testing for Respite Benefits.

2. School Aged Extended Therapies and Early Intervention Programs

Fully aware that effective, appropriate and continual therapies are of central importance for the development of children with disability, in order to improve their health and obtain the maximum level of independence, inclusion, and participation in all aspects of life.

Noting with deep concern that the maximum hourly billing rates for School-Age Extended Therapies are forcing families to top up the hourly rates.

Recognizing that being able to pool therapy funding and allocate funds as needed to OT, PT and SLP would greatly benefit children with disability as this would improve and increase their access to effective and suitable therapies.

Taking into consideration there are various therapies children are benefitting from, that fall outside of these three funded options but families do not have equal access to them due to financial barriers.

Alarmed by the current state of Early Intervention Programs which are dreadfully underfunded, with therapists' workloads increasing and some children only having access to therapists once a month.

Emphasizing that complex children require appropriate and specialized therapy and the Early Intervention Programs are not always able to meet these needs

Deeply concerned about the inequality of BC children's access to funding between the At Home Program and Autism Funding.

'BC Parents of Complex Kids' **recommends** that MCFD:

- Improves the funding for School Age Extended Therapies by providing the opportunity to pool therapy funding so that they can focus on the specific needs of their child, improving their health and helping them obtain the maximum level of independence.
- Removes the maximum hourly billing rates placed on School-Age Extended Therapies.
- Allows caregivers to decide which types of therapies would benefit their children the most by expanding the range of therapies covered.
- Provides funding for private therapies in the preschool age years considering that having access to appropriate early intervention is a fundamental human right of children with disability.
- Monitors more closely the contractors hired by MCFD to provide Early Intervention Programs to our children.

3. Medical Equipment / Medical Supplies/ Biomedical Equipment/ AAC Equipment

Deeply concerned about the current state of funding for medical equipment that improves our children's health, quality of life and allows them to participate in society and fully enjoy all human rights and fundamental freedoms.

Recognizing that the cost of mobility and positioning devices has tremendously increased in the last couple of decades.

Alarmed that families need to apply to charities or pay out of pocket for basic medically necessary equipment.

Taking into consideration that some charity organizations such a "President's Choice Children's Charity", that used to provide funding for mobility and positioning devices are no longer providing funding for this equipment.

Concerned that the cost of orthotics is rising beyond the funding maximums.

Fully aware that some children, due to their complex health and developmental needs, require several pieces of equipment in order to improve their health, their quality of life and be able to fully participate in their community.

Convinced that the current equipment loan system is inefficient and too complex to allow a functional and effective circulation of mobility and positioning devices.

Alarmed that medically complex children do not always have access to adequate and appropriate medical supplies and biomedical equipment.

Emphasizing the fact that our children have the right to access and use of Alternative and Augmentative Communication equipment.

Recognizing that AAC equipment can vastly enhance our children's quality of life and can help achieve the fullest possible social integration and individual development.

Deeply concerned about the high cost of the AAC equipment that allows our nonverbal children to communicate and fully participate in society.

‘BC Parents of Complex Kids’ **recommends** that MCFD:

- Increases the funding maximums as needed for each medical equipment funding category to keep up with inflation and cover the full cost of equipment.
- Adjusts the restrictions on pieces of equipment for children that need more than one alternate positioning device or creates new funding categories to capture these needs.
- Reviews and increases the funding maximums for all categories of orthotics to cover the full costs.
- Ensures that adequate and appropriate medical supplies and biomedical equipment are available to all medically complex children and emergency provisions are made for back orders, equipment malfunction etc.

- Provides AAC equipment funding for children who are nonverbal or would benefit from these assistive technologies.

- Engages in discussion with the large BC charities including Variety and the CKNW Kid's Fund in order to further understand who is using these charities and under what circumstances.

- Improves the current equipment loan system and further promotes the circulation of equipment.

4. Accessibility and Safety

Recalling Article 9 of the CRPD on Accessibility.

Emphasizing the fact that a great number of our children are in wheelchairs and therefore need accessible vehicles and home adaptations to be able to participate in society in a dignified and safe manner.

Recognizing the high costs and financial burden on families, especially those in the lower income bracket, that results from purchasing accessible vehicles and making costly home adaptations or renting accessible housing.

Deeply concerned about the lack of support and government programs directed to aid families with the cost of accessible vehicles and housing adaptations.

'BC Parents of Complex Kids' **recommends** that MCFD:

- Creates a permanent program to help families access funds to purchase accessible vehicles.

- Establishes a permanent program to assist families needing to find accessible housing or fund home adaptations.

5. Family Supports and Communication Mechanisms

Considering that effective communication between the AHP and its users is essential for the effectiveness and efficiency of the service delivered by the program.

Recognizing that the current service delivery model is challenging to navigate and there are gaps in services between ministries.

Deeply concerned about the mental health effects of stress and the emotional toll of parenting complex children.

Taking in to consideration that parents are key stakeholders and valid decision makers since they possess an intimate knowledge of their children’s needs.

‘BC Parents of Complex Kids’ **recommends** that MCFD:

- Implements a communication system between the AHP and its users by creating an Online Portal or other avenue, to allow parents to stay informed, access information with regards to the program as a whole, access specific information about their funding and medical supply orders as well as any changes or updates to the AHP.
- Establishes a cross ministry service delivery model and the addition of case coordinators to support the ability of families to access necessary services.
- Allows an opportunity for AHP families to access funded family counseling.
- Establishes the AHP Parent Engagement Group as a permanent structure in order to facilitate ongoing discussion between the AHP and families.