The Parents and Professionals Plan

April 3, 2023



A plan to transform services for BC's children and youth with disabilities

Introduction

Over the past year, the BC Government has made key decisions about funding and services for children and youth with disabilities *without us*. They tried to force all children into centralized hubs and end individualized funding. Parents, caregivers and professionals united to stop their plan and the BC government has now committed to a transformed system. We agree with Premier Eby that "every child in BC should have the supports they need to thrive".

We are parents and professionals raising or working directly with these children and we have a proposal. *The Parents and Professionals Plan* (the P + P Plan) has been built based on our lived experience.

Since 2002, parents of children with autism have received individualized funding, and because of this have had the power to make choices, and to build and train teams of professionals that work with their children. All children with disabilities deserve this.

The P + P Plan recognizes that Indigenous peoples will be advancing and developing their own plans for transformation of services for children with disabilities, based on processes currently underway to recognize and implement Indigenous laws and jurisdictions, and meet the standards of the *United Nations Declaration on the Rights of Indigenous Peoples*. As Indigenous peoples determine and develop plans, we believe the P + P Plan can be a transitional source of support.

We agree that a transformed model of services for children with disabilities is long overdue. The P + P Plan is the right way forward for children and families.

Our Vision

Adequately funded family and child centered services and supports that meet the needs of every child, based on best practices and evidence, provided by trained and skilled workers, and upholding the inherent dignity of every child and all human rights standards.

Autism BC survey: 1,563 parents/caregivers



Our Principles

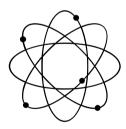
The P + P Plan is based on the following principles:



 Child and Family at the Center - Holistically surrounding each child with the supports, services, and love they need.



• Lived Experience - Valuing the wisdom of the lived experience of children, siblings, parents, and caregivers.



• Evidence-Based - Grounded in a scientific foundation of best evidence, professional advice, and the latest research and findings.



 Rights-Based - Upholding the dignity of each child, respecting their individuality, and meeting all human rights standards, including those in the Convention on the Rights of the Child and the United Nations Declaration on the Rights of Indigenous Peoples.

Our Model

The P + P Plan has three main pillars

Assessment One stop diagnosis

Access
Individualized funding for all

DeliveryIntegrated service delivery

Assessment

What does today look like?

Access depends on where you live and how much money you make.

There are painfully long wait lists for assessment and diagnosis of children with neurodevelopmental challenges and the BC guidelines are unnecessarily restrictive and expensive.

Early intervention is the **best** intervention and BC is failing families and harming children by delaying diagnoses.

Current BC guidelines for assessment and diagnosis of autism are arbitrary, apply only to BC, and result in greater costs and delays for assessment and treatment for BC families.

In other provinces and countries, qualified professionals are trusted to use appropriate methods and render diagnoses by current scientific and professional standards.



Assessment

What does tomorrow look like with the P + P Plan?

One doctor, one standard

In most circumstances, a single qualified diagnostician can render an accurate diagnosis, with more extensive multidisciplinary assessments reserved for more complex cases.

By modifying the BC guidelines and eliminating the current double standard between public and private assessments, the waiting list for assessment would be dramatically reduced. One qualified specialist (a pediatrician, psychiatrist, or psychologist), whether private or public, should be sufficient to make a diagnosis and access treatment.

Family physicians, public health nurses, nurse practitioners, and speech-language pathologists can reliably identify children 'at risk' for ASD and other neurodevelopmental disabilities. A provisional diagnosis should be sufficient to access some immediate assistance before a specialist assessment can be completed.

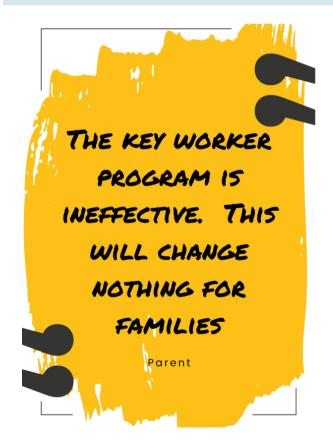
Access

What does today look like?

Without individualized funding parents have **no choice** but to use generalized services. Families and professionals have no influence over the contracts the government makes with service organizations or what services are provided.

These services are not uniquely designed for the child's specific needs, nor delivered in a way that is beneficial for the family.

There is always a wait list.



MCFD recently doubled the budget for the FASD Key Worker Program, adding bureaucratic roles, but not any direct therapy for kids.

Fund families not MCFD

Access

What does tomorrow look like with the P + P Plan?

Individualized funding for all children with disabilities

The success of individualized funding will be expanded exponentially. Parents and caregivers in all disability communities will have the power to choose services for their children directly.

When parents have control of funding, people and organizations with expertise in different disabilities will evolve and create capacity. More children will get better services tailored to their specific needs.

For example: In 2002, BC had only four behaviour analysts. Today there are almost 500 working with autistic children. All children with disabilities deserve increased capacity of specialists trained to their specific needs.

For over 20 years in BC, individualized funding has achieved better outcomes for more children than other models of providing services.

Expansion of the At Home Program

Improvement and expansion of this individualized funding program for children with severe disabilities who live at home and are assessed as dependent in at least 3 of 4 functional activities of daily living - eating, dressing, toileting and washing.

Additional services for profound disability

Children with more profound levels of disability have higher needs. A small percentage of children have such profound and complex challenges that they need 24/7, full on care.

Expansion of the FASD individualized funding program

Give individualized funding to all families who applied for the Asante Centre/Carrier Sekani Family Services/MCFD grants and extend this option to children with other neurodevelopmental disabilities.

Access

Virtues of Individualized Funding

Choice: Parents and caregivers can choose who supports their child, the services they receive, and when and where they are delivered.

Accountability: Those who deliver services are directly responsible to the child, parents, and caregivers.

Efficiency: The relationship between the child, family, and service provider is direct, which reduces paperwork, bureacracy, and administrative costs.

Dignity: Upholds the dignity of each child by supporting the tailoring of services to the specific context and needs of each child.

Well-being: Supports the well-being of families and children, including better mental health outcomes, by respecting the essential roles, responsibilities, and leadership of parents and caregivers.

Individualized funding saves \$ because parents stretch every \$

Delivery

What does today look like?

There is a tragic lack of access to therapeutic services in rural regions, and long delays exist everywhere in BC.

Parents have to work through the complexity of multiple ministries that are not aligned in policies or practices.

There are not enough trained providers, job incentives, or clear career pathways for disability specialists.

Families experience fear and trauma when dealing with MCFD, a child protection focused ministry. This especially harms Indigenous peoples.



Delivery

What does tomorrow look like with the P + P Plan?

One child, one path

Parents will only need to engage with one government ministry for Assessment, Access, and Delivery.

Navigating different ministerial programs and protocols will no longer be a never ending maze for parents.

Moving responsibility for children with autism and other neurodevelopmental disabilities to the Ministry of Health would allow for individualized funding similar to the Choice in Supports for Independent Living Program. This model is well suited for rapid implementation, is in compliance with human rights, and fully meets Ministry needs for accountability.

Direct service in underserved regions

Incentives and funding to motivate disability specialists to move to northern and rural regions, reflecting BC's incentive model for family doctors.

Revitalized training and recruiting of service providers Investment in education and training of disability specialists and provision of small business incentives for local, independent operators.

What will it cost?

There are three answers to this question:

- 1.It will cost more than the government is currently spending, but less than an equivalent centre based program. As MCFD has confirmed, there has not been enough investment in children with disabilities.
- 2.Long term, it will cost less than the government is currently spending. The consequences of not paying for services and interventions in childhood is that all of society pays more for welfare, social services and institutional care in the future.
- 3.Almost without exception, individualized funding is more cost-effective, leads to better outcomes and is preferred by parents and caregivers.

"Without a substantial infusion of new funding, wait lists will be even longer, service quality will be even more compromised, and CYSN and their families will suffer as a result."

2023 Report released by the Representative for Children and Youth

In Support of P + P Plan

We welcome comments, questions and endorsements of the P + P Plan.

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Contact us

We are parents, caregivers and professionals that work with and care for children and youth with disabilities. We appreciate any and all help that you can give in distributing this plan.

Please contact us for more information about supporting the P + P Plan.

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