

Update: System of Services for Children and Youth with Special Needs

September 2010



September 9, 2010

Honourable Bill Barisoff
Speaker of the Legislative Assembly
Suite 207, Parliament Buildings
Victoria BC V8V 1X4

Dear Mr. Speaker,

I have the honour of submitting this update report on the System of Services for Children and Youth with Special Needs, to the Legislative Assembly of British Columbia.

This report is prepared in accordance with Section 6(b) of the *Representative for Children and Youth Act.*

Sincerely,

Mary Ellen Turpel-Lafond

Representative for Children and Youth

pc: Mr. E. George MacMinn, QC

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Clerk of the Legislative Assembly

Ms. Joan McIntyre

Chair, Select Standing Committee on Children and Youth



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Introduction

The Representative for Children and Youth's mandate includes encouraging government and service providers to work toward providing children and youth with special needs the best possible system of supports – including recognizing their rights to safety, well-being and the respect of society.

This is the third report issued by the Representative for Children and Youth (RCY) looking at the responsiveness and effectiveness of services to B.C. children and youth with special needs.

In February 2008, the Representative released *Monitoring Brief: System of Services for Children and Youth with Special Needs.*¹ The document examined how the Ministry of Children and Family Development (MCFD) and Community Living BC (CLBC) delivered services to children and youth with special needs and their families. The report identified six areas of key concern and provided 12 recommendations to strengthen the responsiveness and accountability of the system. As well, the Representative urged that this work be given greater priority.

The Representative's update report² on this matter was released in November 2008. It noted very limited progress implementing the recommendations in the previous document. Of the 12 recommendations, four were assessed as "planning underway," three as having "limited progress," two as "no progress," one as "initial planning underway," and one as "implementation underway." (One other recommendation was not assessed as it requires regulatory and legislative changes.)

In June 2008, prior to the release of the update report, the B.C. government announced changes in ministry responsibilities and a transfer of services for children and youth with special needs³ from CLBC to MCFD. The transfer was originally scheduled to be implemented on March 31, 2009, but this date was later changed to Oct. 31, 2009.

This third report on the status of the service delivery system for children and youth with special needs provides an overview of key changes to the system since June 2008 (when government announced the pending responsibility changes and transfers), and considers how planning and implementation for those changes address concerns identified in the Representative's original review of the system. A program review including the outcomes for children and youth with special needs accessing services and supports is not feasible at this time due to significant changes underway to the service delivery system.

http://www.rcybc.ca/Images/PDFs/Reports/Monitoring%20Brief%20-%20Special%20Needs%20-%20Feb%2008.pdf

² http://www.rcybc.ca/Images/PDFs/Reports/Special%20Needs%20Update08%20FINAL.pdf

³ Children and youth with special needs refers to "those children and youth up to 19 years of age who require significant additional educational, medical/health and social/environmental support — beyond that required by children in general — to enhance or improve their health, development, learning, quality of life, participation and community inclusion." Definition is taken from from MCFD website, www.mcf.gov.bc.ca/spec_needs



This report contains three sections:

- a status summary of the service delivery system for children and youth with special needs
- general observations based on a review of government's planning and implementation methods to transfer children and youth with special needs services to MCFD, and on consultations with children and youth with special needs stakeholders, including Aboriginal stakeholders⁴
- recommendations for government as it moves forward in the long-term service transformation of the service delivery system.

⁴ Consultation with members of the RCY Advisory Committee for children and youth with special needs; Aboriginal stakeholders and representatives from delegated Aboriginal Agencies: Jan. 13 – Feb. 19, 2010



Current Status

1. Transfer of Children and Youth with Special Needs Services

Government's decision to transfer children's services provided by CLBC to MCFD was in response to criticism from families and caregivers that the division of responsibility for services to children and youth with special needs was fragmented and not responsive to the needs of families.⁵

In moving forward, MCFD and CLBC engaged in a two-phase approach to the transfer of services for children and youth with special needs.

Phase One was completed on Oct. 31, 2009, with the administrative transfer of all children and youth with special needs services into the existing MCFD service delivery system. This transfer included the movement of staff, contracts, budgets and other administrative matters from CLBC to MCFD. At that time, it was estimated that 11,000 children and youth with special needs transferred to MCFD's responsibility.

Phase Two began on Nov. 1, 2009, with a focus on the longer-term transformation and stabilization of the provincial service delivery system for children and youth with special needs.

The new model seems to be consistent with priorities identified in MCFD's *Strong*, *Safe and Supported: A Commitment to BC's Children*,⁶ and the multi-ministry document, *Children and Youth with Special Needs: A Framework for Action*.⁷ The model addresses service delivery workflow by establishing functional roles and responsibilities to which all regions are expected to adhere. It also provides MCFD regions with the opportunity to vary the design of the provincial model to meet the unique needs of their areas.

The service delivery model also indicates that there is no intention to combine child protection and children and youth with special needs caseloads, which is positive for families. Children and youth with special needs and their families will continue to be able to access services without involvement of a child protection intake worker or any other investigative process.

As MCFD is implementing the service delivery model, it is also moving forward with the introduction of *Child* and *Family Support*, *Assessment*, *Planning and Practice* (CAPP). CAPP will initiate practice change across the child and family development system, including how supports and services are offered to children and youth with special needs and their families. Unfortunately, details on how CAPP aligns with the priorities set out in the service delivery model are unknown at this time.

⁵ Information Note: Transition Process, Ministry of Children and Family Development (September 2008).

⁶ British Columbia, Ministry of Children and Family Development. (2008). Strong, Safe and Supported: A Commitment to BC's Children and Youth from http://www.mcf.gov.bc.ca/about_us/pdf/Strong_Safe_Supported

⁷ British Columbia, Ministries of Children and Family Development, Education, and Health Services. (2008). *Children and Youth with Special Needs:* A Framework for Action from http://www.mcf.gov.bc.ca/spec_needs/pdf/CYSN_FrameWorkForAct



2. New Initiatives

At the end of 2009, the government introduced new initiatives to support youth with special needs.

Youth Transitioning to Adulthood

To ensure continuity of services for youth turning 19 and transitioning to CLBC adult services between Nov. 1, 2009 - June 30, 2010, CLBC and MCFD entered into an eight-month Memorandum of Understanding. It outlined the shared responsibility for these youth during this critical transition time.

To further address ongoing concerns about service options for youth ages 14–25 with special needs receiving services from MCFD and delegated Aboriginal Agencies, a *Cross-Ministry Youth Transition Planning Protocol for Youth with Special Needs* was developed jointly by nine government organizations.⁸ The agreement outlines a collaborative approach to transition planning.

CLBC and MCFD also entered into an agreement that outlines the roles and responsibilities of both parties and describes the establishment of Joint Regional Management Committees to collaborate and exchange information related to youth transitioning to adult services.

Expanded Eligibility

A new regulatory amendment took effect on Jan. 31, 2010, expanding the eligibility criteria for CLBC. The new eligibility criteria focuses on adults diagnosed with significant limitations in adaptive functioning⁹ and either a Pervasive Developmental Disorder¹⁰ or a Fetal Alcohol Spectrum Disorder.¹¹ CLBC is providing services to this distinct group of adults through the Personalized Support Initiative – a new service delivery stream that is separate and distinct from CLBC services currently delivered to individuals who meet existing criteria for "mental retardation".¹² The action CLBC took to expand eligibility for this distinct group is a first step in addressing the issues raised by the Representative about lack of supports and services for youth with special needs turning 19 and transitioning to adulthood.

Includes: Ministries of Children and Family Development, Housing and Social Development; Health Services, Advanced Education and Labour Market, Education; Community Living BC; BC Housing; Public Safety and Solicitor General; and Public Guardian and Trustee.

⁹ Having significant limitation in adaptive functioning indicates that an individual has been assessed by a qualified practitioner and found to be three standard deviations below the norm on one of three specific assessments and global scores.

¹⁰ Pervasive Developmental Disorders includes Autism, Asperger's Syndrome, PDD-NOS, Rett's Syndrome and Childhood Disintegrative Disorder.

¹¹ Fetal Alcohol Spectrum Disorders includes Fetal Alcohol Syndrome, Partial Fetal Alcohol Syndrome and Alcohol Related Neuropathy Disorder.

¹² Diagnostic and Statistical Manual of Mental Disorders, fourth Edition. Copyright 1994 American Psychiatric Association from http://www.behavenet.com/capsules/disorders/mentretard.htm



3. Policy and Budget Changes

Autism

In 2009, MCFD announced changes that directly impacted the delivery of services to families and caregivers accessing supports and services through the Autism Funding Program.

- MCFD eliminated the Direct Funding option, which provided funding directly to families through a
 funding agreement. All families will now operate through the Invoice Payment option where government
 provides payment directly to service providers.
- Effective April 1, 2010, the Autism Program for children under age six provides families with up to \$22,000 annually per child to assist in purchasing eligible autism intervention services and therapies. This is an increase of \$2,000 annually.
- Effective Jan. 31, 2010, MCFD discontinued funding the Early Intensive Behavioural Intervention (EIBI) programs. EIBI programs were intensive intervention programs for children with Autism Spectrum Disorders (ASD) who were five years of age or younger. The programs were based on Applied Behaviour Analysis and served 70 children in seven communities at a cost of approximately \$5 million annually. Families receiving the EIBI at the time the program ended were transferred back to the regular Autism Funding program. MCFD indicated that approximately \$1 million will be redirected toward the creation of a new provincial outreach program to improve access to professional services, particularly in rural communities. Details of this program have not yet been made public.

Provincial Advisors

In late 2009, MCFD discontinued the role of the three Provincial Advisors for the Infant Development Programs (IDP), Supported Child Development Program (SCDP) and Children's First. The Provincial Advisors from the IDP and SCDP linked families and service providers with resources and up-to-date information on evidence-based early intervention practices. They also provided expert advice and training opportunities to professional consultants. The Provincial Advisor for Children's First served to network their 45 community-based initiatives throughout the province.

MCFD indicated the discontinuation of the role of the three Provincial Advisors was done to protect direct front-line infant development services to children and families, and will not result in any interruption in services to clients. The role of the Provincial Advisor for the Aboriginal Infant Development Programs remains in place to increase support to Aboriginal Infant Development Program consultants.



Observations

In reviewing planning and implementation methods undertaken by government, and in consultation with children and youth with special needs stakeholders and representatives from delegated Aboriginal Agencies, the following observations can be made:

- 1. Government has made changes to the service delivery system for children and youth with special needs, which show promise in addressing the following concerns raised by the Representative.
 - The lack of support for families and caregivers who require or desire assistance in planning for, implementing and coordinating the variety of services and supports available to them
 - The new service delivery model speaks to a service component of providing family support, service coordination and problem resolution through "key worker or case manager" roles. The job description for children and youth with special needs workers reinforces these roles. It articulates the requirement, when needed, to provide families or caregivers support to plan, implement and manage services and supports to their children over time.
 - The need for clearly articulated and publicly documented strategic and operational roles, responsibilities, relationships, and accountabilities for services for children and youth with special needs
 - MCFD developed an administrative framework that included strategic and operational roles, responsibilities and relationships for services to children and youth with special needs. MCFD forwarded administrative information, such as the transferred budget dollars and staff positions, to the MCFD children and youth with special needs stakeholders group.
 - Disputes regarding mandates and jurisdictions between MCFD and CLBC impact the delivery of supports and services to families and caregivers
 - The transfer of children services to MCFD and the introduction of guidelines and agreements address the concerns raised in this recommendation.
 - The need to reduce vulnerability for youth during the transition to adulthood
 - The introduction of the previously discussed protocols and agreements provides a foundation on which to develop inclusive, coordinated transition planning to be implemented across regions.
 - A Youth Transition Planning Protocol Implementation Working Group has also been established with the intent to focus on areas such as the development of implementation tools, information material for youth and families, and training opportunities for practitioners.
 - CLBC's new Personalized Support Initiative is another positive step toward addressing an existing gap



in services to adults with developmental disabilities. However, given its strict eligibility criteria, there are concerns that only a small number of youth aging into adulthood with developmental disabilities will be eligible to access these services. Expanding eligibility is a first step and CLBC is conducting an evaluation to inform next steps.

- Timely and appropriate access to service is a key component of service responsiveness. MCFD wait times are inconsistent with evidence-based wait times for services to children and youth with special needs MCFD has not fully addressed this concern, but continues to work toward building a wait list methodology that will be consistent with the evidence-based system. After completing research, including a jurisdictional review of wait times, MCFD has chosen to use CLBC's existing wait list methodology. MCFD has refined CLBC's "priority ranking tool" in order to implement it into MCFD's existing system. A new MCFD policy, "Determining Priority for Children's Services" and accompanying standards and "Priority for Service Tool" were introduced to provide clarification on the process used to determine the service priority for families who request Family Support Services, At Home Program, Respite Benefits, or staffed residential or Family Care arrangements. There is currently no consistent wait time methodology across all children and youth with special needs services and MCFD should continue its efforts in this area.
- 2. During the transfer process government was inconsistent in the information it shared when, how, what and to whom.

Between June and November 2008, when the transfer of CLBC children services to MCFD was first announced, families and service providers received general information about the transfer process. MCFD sent four letters to families and caregivers outlining the transfer. Copies of the letters were posted on the MCFD website.

After November 2008, MCFD's provincial office stopped providing update information to families and service providers, leading to speculation that the transfer process had been halted and children services would remain with CLBC. It was not until one month prior to the transfer of services from CLBC to MCFD, in October 2009, that government provided another communication update, which confirmed to stakeholders that the transfer was going ahead as scheduled.

Feedback from stakeholders indicated that the lack of consistent, updated information leading to the transfer of children services created unnecessary stress and uncertainty for the children and youth with special needs community, particularly for families and caregivers already challenged with supporting their children.

Stakeholders also indicated that the limited communication was not disseminated throughout the entire children and youth with special needs community. Many service providers such as medical professionals and special needs educators did not receive information from MCFD about the changes to the service delivery system for children and youth with special needs. These professionals often play an important supportive



role as the first point of contact for children with special needs and their families, and require the most current information regarding any changes to the services delivery system.

Concerns were also expressed that there were significant inconsistencies in when, how and what information was provided to stakeholders by MCFD regional staff across the province. The type and frequency of information received by service providers differed depending on which region they operated in.

With the commencement of Phase Two, MCFD regions are tasked with developing regional communication strategies. At this time MCFD is unable to share how these strategies are developed and what steps will be taken to ensure consistent information sharing across the province.

3. MCFD had limited engagement with Aboriginal stakeholders or delegated Aboriginal Agencies during the first phase of the transfer.

At the start of Phase Two, in December 2009, MCFD met with Directors from delegated Aboriginal Agencies to review activities completed during Phase One. At the meeting, MCFD said that Phase Two would include engagement with Aboriginal stakeholders and delegated Aboriginal Agencies. MCFD identified that consultation with Aboriginal stakeholders was imperative during the development and implementation of regional service delivery models for Phase Two. MCFD reports that future engagement with Aboriginal stakeholders and delegated Aboriginal Agencies will occur at the regional level in accordance with the recently released *Aboriginal Service Delivery Change: A Conceptual Framework for Ministry Staff.*¹³ At this time there is little information on how the conceptual framework will be implemented. The Representative does not know how MCFD intends to engage Aboriginal stakeholders in the planning and delivery of services to Aboriginal children and youth with special needs both on and off reserve.

Feedback from the Aboriginal community indicates that MCFD has not yet actively engaged Aboriginal stakeholders or delegated Aboriginal Agencies in the second phase of the transfer process, which is intended to transform and stabilize the new service delivery system. This creates concerns for Aboriginal stakeholders that gaps in services to Aboriginal children and youth with special needs may occur – particularly for those living on reserve – as roles and responsibilities have not been discussed between Aboriginal stakeholders and MCFD.

¹³ The Aboriginal Service Delivery Change: A Conceptual Framework for Ministry Staff, is an internal guide for ministry staff in moving forward with the ministry's key priority of supporting First Nations, Métis and other Aboriginal people in developing and delivering a service approach based on their culture and traditions. The principles are adapted from the Touchstones of Hope for Indigenous Children, Youth and Families. The framework is not meant to guide Aboriginal people and has not yet been implemented by MCFD.



4. MCFD's progress has been slow in developing and implementing an approach to eligibility that is child-development centred and based on functioning.

As reflected in the Representative's November 2008 report, MCFD was working on a new functional-based eligibility model for services to children and youth with special needs. A functional approach looks at how a person is able to function in any given situation as opposed to a diagnostic approach that focuses on the person's diagnosis. For example, because autism is a spectrum disorder two youth diagnosed with autism can function very differently – one may require minimal assistance while the other is very vulnerable and requires 24/7 support. This new model was to be put into operation once a comprehensive approach was finalized.

Since 2008, MCFD has continued to work on jurisdictional review and best practice research regarding different functional needs assessment models. MCFD reports that work in this area has slowed due to priority being given to the transfer of services for children and youth with special needs, and for youth transitioning into adulthood.

As discussed in the Representative's previous two reports, diagnostically driven approaches to eligibility can exclude many children and youth with comparable needs who do not meet the diagnostic requirements for accessing services. This concern continues to resonate within the children and youth with special needs community. Feedback from stakeholders indicates a strong interest in moving toward a more inclusive functional-based approach in all areas of the service system.

5. Government has not adquately addressed gaps in advocacy support for youth aged 19 to 24 years.

The Advocate for Service Quality provides assistance to adults with developmental disabilities who could benefit from the intervention of someone working independently from CLBC. The role of the Advocate for Service Quality has recently expanded to provide assistance to youth with special needs and their families as well. It is important to note that the Advocate for Service Quality reports to the Minister of Housing and Social Development. As such, the ability to challenge administrative or policy decisions is constrained.

The independent Office of the Representative for Children and Youth provides information, advice and support to all children, youth and their families who need help in dealing with designated services. This also includes youth under the age of 19 with special needs and their families.

Currently the Representative's mandate does not include youth aged 19 and older.



Government has indicated "that approximately 8.3% of the youth population [youth with special needs] in B.C. will require transition planning support, with 4,400 14-year-old youth expected to begin the transition planning process every year." Conversely, CLBC projects that on average 549 youth with developmental disabilities will turn 19 and become eligible for CLBC services each year. Based on these figures, it can be assumed that the vast majority of youth with special needs will not be eligible for CLBC services.

The Representative continues to be concerned for the safety and well-being of the group of youth with special needs that have aged out of children's services and are left without adequate independent advocacy support. Of particular concern are youth transitioning out of care that were previously supported as children through services for children and youth with special needs. When these young people turn 19 years of age, government ceases to be their guardian and many will not have a natural advocate to support them in navigating adult services in the community. Individuals in this population are often transient.

The network to stay in touch with and engage these young people is simply not there under the proposed model – especially for those very vulnerable young adults with special needs who are not eligible for CLBC services. Receiving support from an independent advocate who has expertise in this situation would assist in ensuring these young people a safe and effective transition into early adulthood.

As an individual working without staff, the Service Quality Advocate's capacity to expand her scope to include the significantly larger group of young adults with special needs is severely compromised. The question remains whether adequate resources will be available to support the expanded role.

Funding commitment to support the expanded role of the Service Quality Advocate is not clear, and the Representative remains concerned that decisions about services and advocacy support will be driven by budgetary demands and not based on the needs of children and youth with special needs and their families. While the Representative has the ability to assume this responsibility, it is outside of her legislative mandate.

¹⁴ British Columbia, Ministry of Children and Family Development, *Cross-Ministry Youth Transition Planning Protocol for Youth with Special Needs* (2009). http://www.mcf.gov.bc.ca/spec_needs/pdf/transition_planning_protocol.pdf. Pg 5.

¹⁵Average number of youth turning 19 based on CLBC's projected # of children turning 19 and becoming eligible for CLBC services in fiscal years 2010/11 - 2012/13. Community Living BC: 2010/11 - 2012/13 Service Plan. Pg 16



Moving Forward

MCFD, the Ministry of Housing and Social Development and CLBC are to be commended for achieving their goal of assuming responsibility for children services from CLBC without significant service disruption and for conducting extensive planning in preparation for the transfer. It is noteworthy that the ministries and CLBC also identified areas of potential risk and developed strategies to support the most vulnerable children and youth during this process.

However, there were some lessons learned coming out of the transfer process that could benefit MCFD's work in Phase Two. Out of the 12 recommendations from RCY's original report in February 2008, the Representative has identified five areas that require greater priority and more work. The Representative recommends that while MCFD is engaged in its transformation process the following should be addressed:

1. Consistent and Ongoing Communication

Over the past five years, families and service providers for children and youth with special needs have experienced numerous shifts and long-term indecision in policy direction and service provision. It is critical that further uncertainty does not occur as MCFD transforms its service delivery system. Although the initial transfer of children's services went well, the limited and disparate communication caused unnecessary anxiety and stress for stakeholders and left some without any knowledge of the transfer at all. In order to prevent similar issues from re-occurring in MCFD's five regions, immediate attention is required to create a consistent communications plan. The plan should ensure that:

- regular communication updates are sent to stakeholders. These should be consistent among all regions so that the same information is provided to people at the same time
- practitioners working directly with families with children and youth with special needs, including
 partners from the Framework for Action such as medical practitioners and special needs educators,
 have the most recent information on policies and changes to the children and youth with special
 needs service delivery system.

2. Immediate Aboriginal Engagement

Aboriginal engagement did not successfully occur during the first phase of the transfer process, so it is critical that MCFD immediately engage in a coordinated effort with Aboriginal stakeholders. This must be done to define operational roles and responsibilities, and mitigate possible gaps in service provision on and off reserve. This is particularly important for Aboriginal youth with special needs transitioning



to adulthood. As operational guidelines have not been established between MCFD, CLBC, and Aboriginal stakeholders, there is a risk that effective planning for this vulnerable population will not occur. In fact, one delegated Aboriginal Agency has already chosen to initiate discussions with MCFD and CLBC to establish a regional operational agreement between the three parties to address this unmet need.

3. Implement a Functional-Based Approach to Eligibility

The implementation of a functional-based approach to accessing services for all services to children and youth with special need is in line with government's *Children and Youth with Special Needs: A Framework for Action* document, in which government states it intends to "[f]ocus services on the functional needs of children, youth and their families." ¹⁶

Work on a functional-based model for accessing services was slowed to support the transfer of children's services and the implementation of initiatives to support youth transitioning to adulthood. However, given the importance of basing service access on children's functional needs, the Representative urges MCFD to give the development and implementation of a functional-based model a greater priority.

4. Advocacy Support for Youth with Special Needs Transitioning Out of Government Care

The Representative remains concerned that adolescents living out of the parental home may not have the ability to plan or seek assistance independently. These youth could require a level of support that is beyond the scope or capacity of the Advocate for Service Quality. This would include many vulnerable youth with special needs that do not have a network of supports, are transient and unable to independently access resources available in the community – including the Advocate for Service Quality. Receiving support from a fully independent advocate who has expertise in this situation would assist in ensuring these young people have a safe and effective transition through early adulthood.

The Office of the Representative currently provides advocacy support for this population of vulnerable adolescents up to 19 years of age. Expanding the Representative's mandate to include youth up to 24 years of age would provide greater continuity within the service delivery system and ensure the safety, support and well-being of this population of former children in care.

¹⁶British Columbia, Ministries of Children and Family Development, Education, and Health Services. (2008). *Children and Youth with Special Needs: A Framework for Action.* Pg 10.



5. Focus on Quality Assurance

Despite delays in the implementation of MCFD's Integrated Case Management system to support integrated decision-making and reporting, the ministry should give a higher priority to the accountability issues identified by the Representative in her February 2008 report. Work has not progressed on data collection and reporting in any meaningful way. For example, MCFD is still unable to report on how many children and youth are served, at what cost and with what outcomes, and measurements of service effectiveness are still not captured. It is important that there be data available for accountability and quality assurance purposes while implementation of MCFD's Integrated Case Management system is underway. This includes capturing data relating to children and youth with special needs, to monitor service utilization and standardized outcomes for children and youth across programs and services.

The Representative's previous two reports on this issue focused on the accountabilities of MCFD and CLBC with respect to the delivery of services to children and youth with special needs. The Representative's observations and recommendations in those reports stemmed from a review of how MCFD and CLBC delivered services to children and youth with special needs.

As described in this report, significant changes have occurred with the transfer of children's services from CLBC to MCFD. The Representative is pleased that a number of her recommendations have been addressed by the transfer and by initiatives implemented by MCFD and CLBC.

As MCFD continues to stabilize and transform the new service delivery system for children and youth with special needs, the Representative will continue to follow their progress. Responsiveness and effectiveness issues, such as communication, Aboriginal engagement, quality assurance, and accountability will be monitored within the context of the new service delivery system. The Representative will also review how CAPP will affect practice change across the children and youth with special needs service delivery system. The Representative is optimistic that MCFD will continue to make progress towards building a stronger system of support for children and youth with special needs and their families or caregivers.