

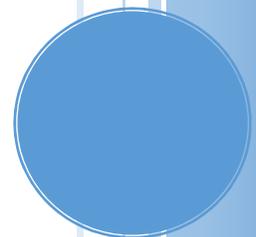
Parents for Children's Mental Health

SUPPORT. EDUCATE. EMPOWER.

THE POSITION OF FAMILIES ON TRANSFORMATION OF THE CHILD AND YOUTH MENTAL HEALTH SYSTEM

*A system that makes sense.....from the perspective of those it
needs to make sense to the most.*

A critique on "Moving on Mental Health: A system that makes sense to children, and youth". Families participated in a comprehensive survey and consultations to provide informed perspective to what is truly required to reach the goal of a "system that makes sense" for those it needs to make sense to most.



The Position of Families on Transformation of the Child and Youth Mental Health System

A system that makes sense.....from the perspective of those it needs to make sense to the most.

Executive Summary

For decades, the complex issues surrounding child and youth mental health (CYMH) in Ontario has been discussed, researched, and reported on. Policy makers, researchers, service providers, and multiple other professionals have been asked to make recommendations to improve the CYMH system, to point out what is wrong, what is needed to fix it, and how it should be done. In 2011, Ontario launched the Comprehensive Mental Health and Addictions Strategy, which prioritized the needs of children and youth. As part of the initiative, in 2012, the Ministry of Child and Youth Services (MCYS) launched a three-year action plan- Moving on Mental Health: A system that makes sense for children and youth. Their action plan aims to deliver a coordinated, responsive system for children, youth and their families by supporting pathways to care, defining core mental health services, establishing community lead agencies, creating a new funding model, and building a legislative and regulatory framework. With growing evidence to support the benefits of meaningful family and child/youth engagement, we are beginning to see families, children, and youth invited into the conversation to share their lived experience with the CYMH system to inform services. Too often, those voices are muted by the overwhelming presence of those who carry professional weight. While there is a growing recognition of the importance of consulting children, youth and families, meaningful engagement rarely happens in a way that allows for maximum benefit and impact. This paper represents the voice of those families whose input has often been overlooked. It is the position of families in Ontario that the only way to create a “system that makes sense for children and youth” is to have families, children, and youth meaningfully engaged in that process.

Parents for Children’s Mental Health (PCMH) is the only provincial organization that represents the voice of families who are struggling with the unique challenges that come with raising children/youth with mental health disorders/illnesses. PCMH provides support, education, and empowerment to its membership as well as community partners and government. Encouraged by the Ministry of Child and Youth Services’ (MCYS) plan to “transform mental health services for children and youth by creating a system that makes sense”, PCMH undertook to examine the process of transformation to determine if it would translate to a system that really does “makes sense for children, youth and families”. Most importantly, PCMH consulted with its membership to ensure that the voice of families, would be heard in the transformation of the CYMH system.

In August 2013, PCMH conducted a survey of families in Ontario. The survey was developed in collaboration with a steering committee comprised of both family members and professionals in the CYMH sector. The survey included a total of 37 questions and was designed to assess the needs of families who have interacted with the CYMH system. PCMH used its established hubs to connect with family members across the Province which, included families involved in support groups and/or in PCMH community activities. PCMH Leads recruited families in their networks and efforts were made to engage diverse groups to represent the diversity of experience and challenges faced by families in the CYMH system. The survey was open for one month and was made available to families electronically through SurveyMonkey. Survey Monkey allows participants to answer anonymously and only once.

Two hundred and fifty four families completed the survey. Respondents were not required to answer all of the questions, allowing them to opt out when they did not pertain to their situation or, potentially, made them feel uncomfortable. In total, two hundred and twenty four families (88.2%)¹ completed the survey in its entirety.

What is Transformation?

According to the *Merriam-Webster* dictionary, “transform” can mean:

- a. To change in composition or structure;
- b. To change in the outward form or appearance of;
- c. To change in character or condition

The concern of families interacting with the CYMH system, is that transformation will only focus on “changing the outward form or appearance of”. For transformation to truly produce “a system that makes sense to children and youth”, dramatic changes need to happen in composition and structure as well as in character and condition. If change only occurs in the outward form or appearance of our system, it will be true that transformation has taken place, but it will not be transformative to the journey and struggles of many families, children, and youth. MCYS has made the bold statement that their plan will “transform the experience of children, youth and families by creating the best service system [...] The result will be a child and youth mental health system that makes sense to families, and is coherent to teachers, doctors, and all those who work with families to find help”.²

The Moving on Mental Health plan on the surface seem to capture what so many have been saying and recommending for years. However, to transform the experience of children, youth

¹ We encourage you to also view the compendium to this report – the Survey Results – where a complete breakdown of questions answered, and the responses are compiled

² Moving on Mental Health: A System that makes sense for children and youth: Ministry of Child and Youth Services, 2013, page 1

and their families, transformation must occur across all sectors who serve children and youth with mental health disorders/illnesses. It cannot occur only within the Ministry of Child and Youth Services. Should transformation efforts continue to only occur within agencies and providers housed within this Ministry, it is the position of families that transformation will not have occurred, and the transformed system will continue to be one that does not make sense for children, youth, and their families.

Current State of Child and Youth Mental Health Services in Ontario

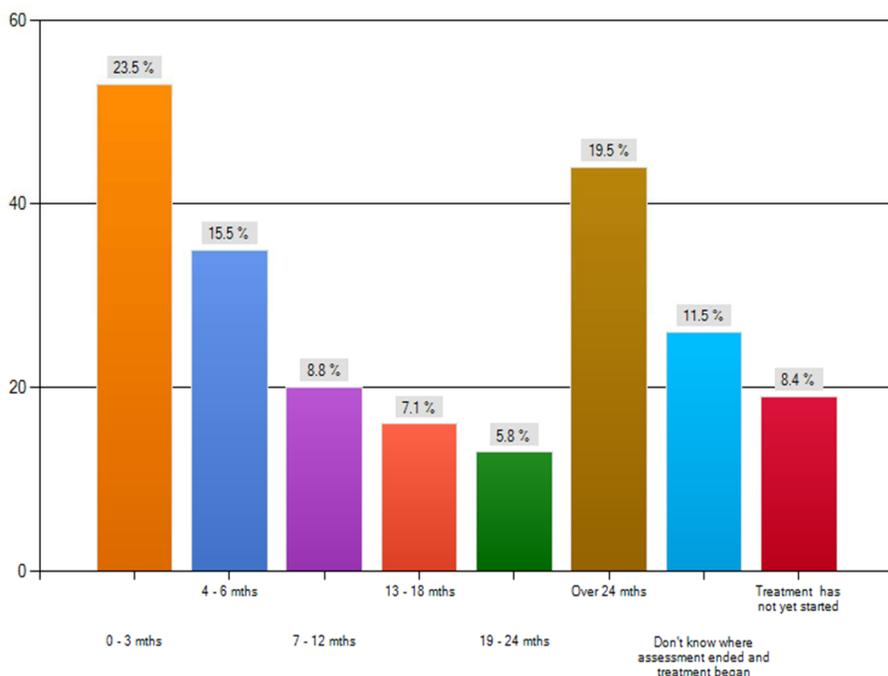
Multiple sources have indicated that approximately 1 in 5 children (20%) in Ontario have a diagnosable mental health disorder or illness. Currently, in Canada, only 1 in 5 children who need mental health services receives them (Canadian Mental Health Association, n.d.) Moreover, when children and youth access services, they can expect long wait times.

23.5% of families waited in excess of 12 months from identification of a concern to an initial assessment

Of those families who waited in excess of 12 months for initial assessment

50.9% of those families waited in excess of 24 months from assessment to treatment³

10. Time from first indication of a concern to first appointment specifically for treatment for a mental health disorder or mental illness



With the knowledge that the best prevention for suicide is early identification and intervention, it is clear that a focus on access and the wait lists to service must be a priority. In addition to wait times, children, youth and families must navigate a complex and often confusing CYMH system to find the help they need. In 2010, the Select Committee on Mental Health and

³ Parents for Children’s Mental Health 2013 Survey results

Addictions produced a Final Report that recognized “there is, in fact, no coherent system”.⁴ They identified that mental health and addiction services are funded or provided by at least 10 different ministries and over 900 different programs or treatment agencies without any person or organization responsible for helping

“After being referred to 15 different agencies, I was referred to one that could provide the treatment my son needed, and was then placed on a 3 year wait list. ”

Family Member

consumers navigate services when and if appropriate services exist. In 2008, The Auditor General Report highlighted a “concern about the lack of consistency in the practices of community mental health providers, and the autonomy with which child and youth mental health providers operate and the resulting patchwork of services.” (Auditor General: Annual Report, 2008). In other words, the Select Committee on Mental Health and Addictions reported: “the situation in which there are hundreds of services, yet individuals are still unable to access care, has left Ontarians confused and frustrated when beginning their search for help.” (Select Committee on Mental Health and Addictions: Final Report, 2010). “Moving on Mental Health: A System that makes sense for children and youth” envisions a very different experience. It has set a “goal to deliver a coordinated, responsive system that makes sense to parents and young people, that is easy to navigate, that enables fast answers and clear pathways to care.”

Pathways to Care: A Co-ordinated and Responsive Service Delivery System

The concerns around lack of coordination, lack of integration, and lack of responsiveness to the needs of children, youth and families are not new. In 2006, The Ontario Centre of Excellence for Child and Youth Mental Health (the Centre) was asked by former Minister of Children and Youth Services, Honorable Mary-Anne Chambers to “continue to dream of a family-centered, systemically integrated and highly effective child and youth mental health system that meets the mental health needs of Ontario’s children and youth. Secondly, to design and propose a road map that will take us there”.⁵ Nearly 8 years ago, the Centre of Excellence consulted with CYMH stakeholders and confirmed that “the system was (and we propose still is) fragmented, detached and beleaguered⁶ and that the need for “an integrated system that eliminates existing

⁴ Select Committee on Mental Health and Addictions; Navigating the Journey to Wellness: The Comprehensive Mental Health and Addictions Plan for Ontarians; Final Report

⁵ Integrating Systems for Child and Youth Mental Health In Ontario: A Proposal to the Ministry of Children and Youth Services (MCYS); The Ontario Centre of Excellence for Children and Youth Mental Health, March 31, 2006, page 2

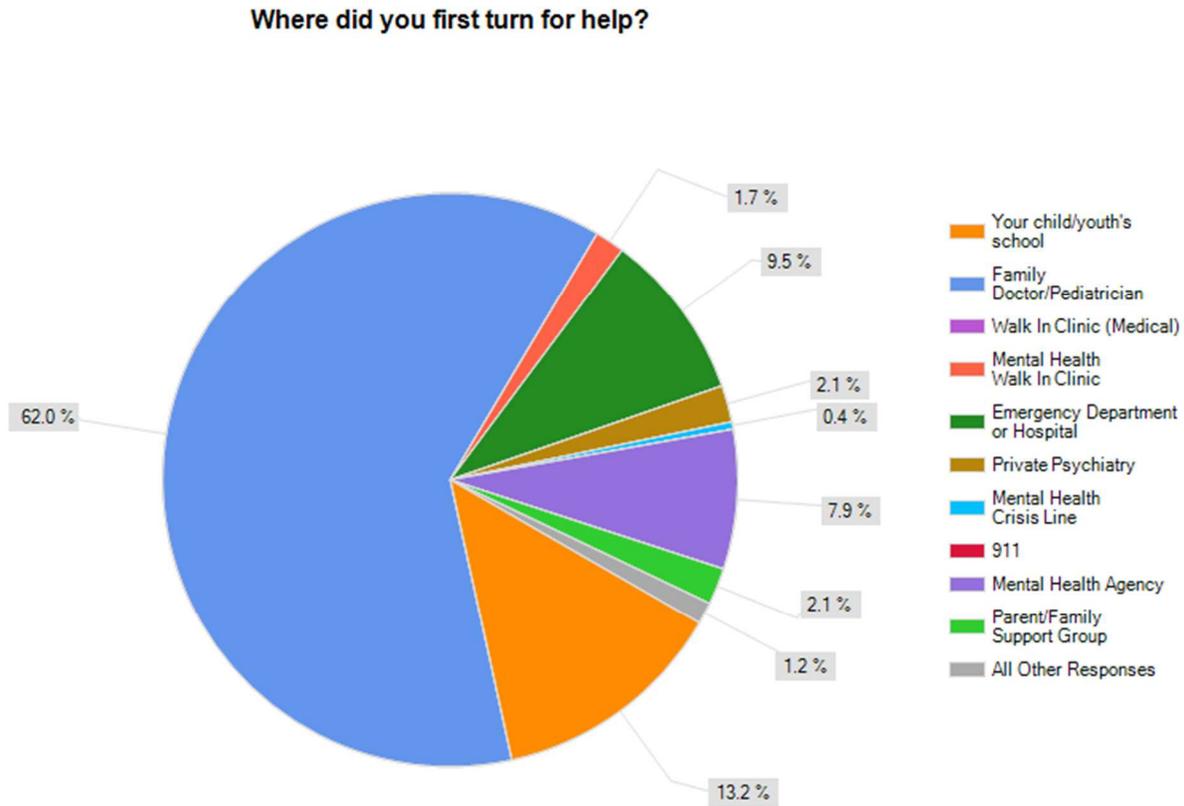
⁶ The Ontario Centre of Excellence in Child and Youth Mental Health; “Integrating Systems for Child and Youth Mental Health, 2006

silos within and between each service sector is paramount”. The PCMH survey showed that on average, families are **waiting in excess of 4 years for access to specialized mental health treatments**, which they largely attribute to the amount of times they are bounced from service to service looking for the appropriate intervention.

Although the issues of wait times and service coordination have been on the table for a number of years, families are concerned that there is still no visible progress. Families want to see an integrated, and cohesive system of care, and they are committed to ensuring that the proposed transformation move from discussions and consultations to definitive, timely, and dramatic change for those using the services .

The current CYMH proposed transformation is being led by the Ministry of Children and Youth Services. Although families applaud the MCYS for a plan that comes as close to action as we have ever seen, families are concerned transformation will only occur within MCYS and fail to address the identified, imminent need for coordinated service delivery across sectors. The PCMH survey indicated that **62% of families first turned to their family doctor or pediatrician once a concern was identified; 13.2% turned to their child/youth’s school, only 9.6% of families actually first sought help from services provided within MCYS.**

The majority of families do not enter the CYMH system through MCYS funded mechanisms, yet MCYS seems solely responsible for initiating “clearly defined pathways to care”. True transformation will require that all ministries serving children, youth, and families make a firm and formal commitment to align with MCYS to ensure a “system that makes sense”. In the absence of a formal commitment across ministries, the goal of a transformed and coordinated system seems unrealistic.



The Centre’s recommendations from 2006 still hold true, if we are truly to achieve an integrated, coordinated, and collaborative system of care for children and youth with mental health disorders/illnesses “there must be a commitment to action” and even more so it is, “essential that the Premier of Ontario spearhead this initiative and **hold each Ministry accountable** for their commitment and participation.”

Defining Pathways to Care

It is clear that the current patchwork system of service delivery must be coordinated; this is an identified priority in MCYS’s transformation efforts as identified in Moving on Mental Health. In addition, pathways to care must be clearly defined, recognizing again that pathways rarely exist solely within in the MCYS. For families, children and youth to experience transformed pathways to care, the plan must transcend ministerial boundaries and funding. **Over 76% of the families surveyed indicated that not knowing where to find help was extremely difficult and created undue stress and confusion in the path to finding support and treatment.**

It is unclear from Moving and Mental Health how pathways will be created to ensure a seamless and coordinated approach that transcends ministerial and funding boundaries and

represents the needs of the children, youth, and their families. A clearly defined pathway to care **cannot** and **will not** be achieved unless **all** points of access are included within the pathway.

As previously mentioned, **only 9.6% of families first presented to MCYS services as the first step to access assessment and/or treatment. Over 74% of families first turned to services within the Ministry of Health and Long Term Care such as family doctors, emergency rooms, or walk in clinics; and 13.2% turned to school programs housed within the Ministry of Education.**

It is apparent that clear pathways to care will not exist unless the two primary access points (Health and Education) are represented and succinctly defined not only to families, but to those professionals whom families first turn for help. It is unclear, in the published documentation to date on the Moving on Mental Health, how multiple entry points will be coordinated and presented in a clear manner. The plan promises a “system that is easy to navigate, that enables fast answers and clear pathways to care”; however, on further examination it appears that changes are based only within MCYS as opposed to the stated “clear and streamlined pathways to care between primary care, schools and community-based supports and services that will help children and youth move through and across the service systems and know what to expect along the way”. With over 90% of children and youth who require CYMH treatment first accessing service outside MCYS’s umbrella, it is clear that there is much work and focus required to ensure a clear pathway to access for CYMH treatment that focuses on entry points outside of MCYS funded services, directing to appropriate pathways within the MCYS system.

Families need to see a clear pathway of care primarily from schools, primary care physicians, and hospitals. Unless these access points are clearly defined with formal protocols instituted to bridge these service providers– families will continue to struggle and they will continue to wait unnecessarily for services while they try to navigate their way into the MCYS funded services.

Our survey also explored whether or not families were truly aware of the number of funding ministries involved in the total care of their children and youth. We learned that:

92.6% of families did not know who funds the services received in community-based mental health agencies

Of those who indicated they believe they knew the Ministry responsible for funding services located in community-based mental health agencies:

20% believed the funding was through the Ministry of Health and Long Term Care

7% believed the funding was through the Ministry of Community and Social Services

1% believed the funding was through the Ministry of Education

Only 17% knew the funding was through the Ministry of Child and Youth Services

This finding was consistent when asked about services and resources accessed through school, and hospital-based treatment and assessments.

Families cannot and should not be expected to have a working knowledge of funding streams in order to appropriately navigate and access services. Families do not have a sophisticated knowledge of these systems, nor should it be required of families. It is the responsibility of those working within the sectors to ensure that partnerships, collaborative protocols, and committed, integrated relationships exist to ensure any point of access allows for seamless entry to MCYS funded services. All child and youth serving professionals, including family doctors, educators, hospital staff, youth justice workers, police, etc., must have a working knowledge of CYMH and be aware of the appropriate resources and referral processes so that system navigation is a seamless process for families. Despite proposed changes, a review of the documentation provided from MCYS to date on the Moving on Mental Health plan does not clearly define how these necessary integrated approaches to access will be created and will continue to require families to have a sophisticated knowledge of the MCYS funded services if they are to access a seamless pathway to care.

CHILDREN, YOUTH, AND THEIR FAMILIES DO NOT AND WILL NOT RECOGNIZE, OBSERVE, OR ACCEPT BOUNDARIES BETWEEN SECTORS OR MINISTRIES IN THE TREATMENT OF CHILD AND YOUTH MENTAL HEALTH.

One of the proposed action items in Moving on Mental Health is the installation of “Lead Agencies” to address current the web of funded services and agencies that provide CYMH services. It is not clear, however, how the Lead Agencies will ameliorate pathways to access and service if entry points are outside of the MCYS funding umbrella, nor how installation of lead agencies will combat the severe lack of integration between primarily Health and Education in the ongoing management and treatment of mental health disorders/illnesses. If Moving on Mental Health plan only addresses the consolidation of “funding envelopes”, transformation will have only taken place in the “outward form or appearance of”. It will not have addressed the burden families and children and youth face when first accessing assessment and treatment. Unless there is a demonstrated, committed, and accountable process in place to ensure development and implementation to the referral pathways, and

pathways to care within communities, defining a clear pathway to care for families will not have been achieved.

“We are constantly in battle for services, even one we have already secured. Our son has a full-time EA. Twice I have had to advocate for it to remain in place, even though everyone agrees he could not function without it. We have had countless staff at agencies close files or transfer files where we end up back at square one without support. Systems in place with police do not require them to read our son's file before engaging him or coming to the house, despite us asking for him to be voluntarily flagged in their system - the mechanisms are there. but not used.”

“All the options presented to us from different avenues were disjointed, piecemeal, little or no follow-up - lots of recommendations with little else - nothing comprehensive and most frustrating of all is no one really listened to US - mental health issues can't be fixed with a pill or '6 easy sessions' . It takes time and continuity. All the 'quick-fix' options we went through over years added to the stress and were practically useless if they didn't make things worse. Long term holistic family support was what was needed and in the long run would have been immensely more cost effective, but virtually no such thing exists.”

Family Member

Wait Lists and Access to Service

The single most debilitating factor for families and children and youth who require mental health treatment remains the wait lists and access to service. Transformation cannot only focus on what services and treatments should be considered “core” but also at processes and wait times for accessing those services. More severe mental illnesses generally requires long term care, yet the Moving on Mental Health plan and the priority of lead agencies seems focused on brief interventions. Quick fixes, rather than services that would allow families, children, and youth to be anchored in care and

parallel the natural ebb and flow of the fluctuating nature of mental illness. The focus is on the beginning stages of care, or the acute phase, but once stabilization is achieved, there are no mechanisms for a seamless re-entry to the care should additional services be required. It would appear that families would be required to start again, re-engage with wait lists, and once again begin a journey of navigation, rather than being provided a fluid continuum of care.

Throughout the survey, families commented on the wait-lists to treatment, and too often, sitting on wait lists only to learn that once the treatment was accessed they were not appropriate, they no longer qualified, and/or they had “aged out”.

For the majority of families surveyed, there was a wait time of 4 years from initial indication of concern, to any specialized treatment or service.

The Ministry of Health and Long Term Care has set provincial targets for wait times for health services, yet the same standard has not been established for mental health services. For example:

Comparison:

Physical Health Treatment	Provincially set target
Pediatric General Surgery	182 days
Pediatric Dental Surgery	188 days
Pediatric Neurosurgery	55 days

Suicide is the leading cause of non-accidental death in Ontario children/youth. Analysis of Statistics Canada data indicates that between 2003 and 2008 youth deaths by suicide were 3 times more than youth death by all cancer related illnesses. Over 90% of those who took their lives had a diagnosable mental illness, indicating that the largest risk factor for suicide is mental illness - yet no standard wait times for access to treatment exist in Ontario. A separate plan on addressing youth suicide prevention is also being undertaken by the MCYS, but again, there is no documentation that illustrates where it is connected or aligned to the Moving on Mental Health plan, nor does it focus on the most primary and effective suicide prevention measure, which is early intervention and treatment of mental illnesses.

The provincially set target wait for dental surgery is 188 days (6 mths), yet our survey indicates that children and youth wait in excess of 4 years for treatment of mental health disorders/illness, even though it is shown through evidence that suicide is the leading cause of death by illness in our children/youth.

After my daughter’s suicide attempt where she was found hanging in our garage, she was on life support for 11 days, and in hospital for over a month. It is a year later and we still have not seen a psychiatrist or are receiving treatment, we just wait.....

Family Member

The priority of defining core services⁷, has to also include defining and provincially setting wait times appropriate for accessing treatment for potentially life-threatening illnesses. Steps must be taken to address the inequity that currently exists for children/youth accessing health services compared to those requiring mental health services. Families encourage the MCYS to follow the lead of the Ministry of Health and Long Term Care to determine standard wait times as well as establish standardized measures for collecting data on whether or not these goals are being achieved. Currently, there is no standardized measure to collect data on wait times, and to adequately address the issue of wait times and access to service. Consistent, standardized measures for monitoring access and wait times for families across the Province must be a priority to ensure the success of transformation.

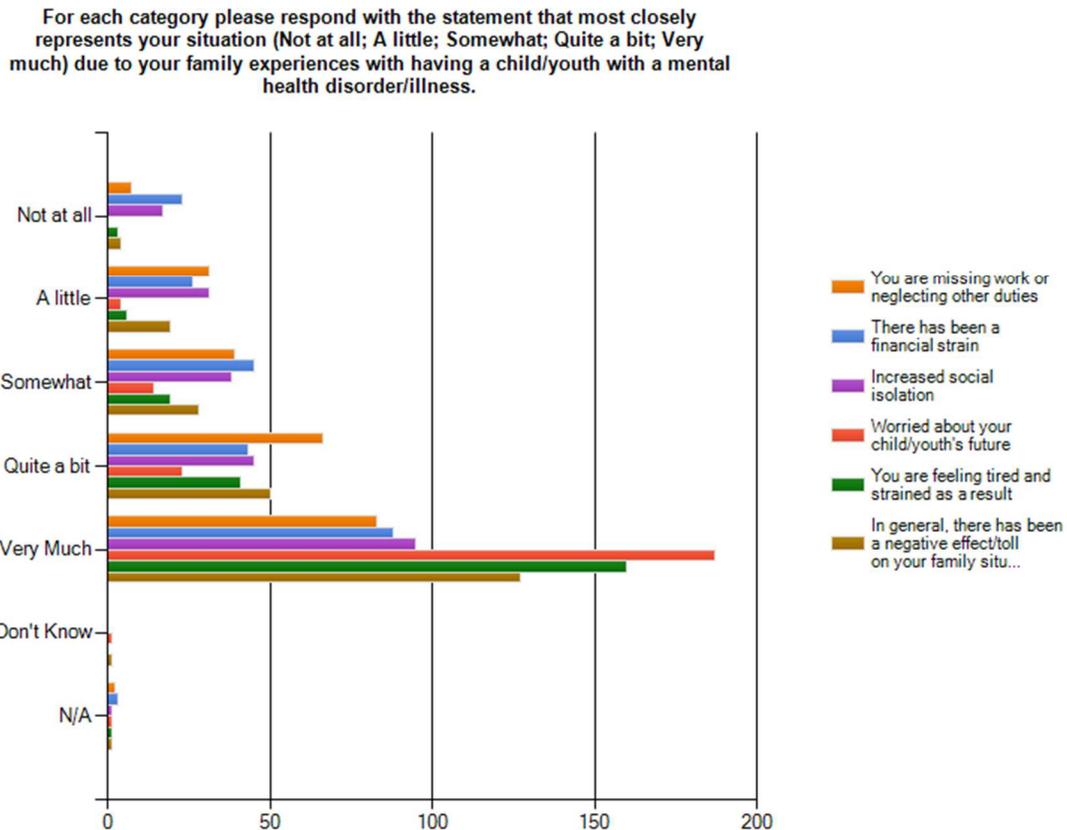
The Family Experience

Transformation of CYMH services will not be realized unless the current experience of those who have accessed and utilized these services is fully understood. To transform the CYMH system, the key issues that need to be addressed must be identified not only from a service delivery point of view but by the consumers of the services if it is going to “change in composition and character”.

The current system is designed in a way that overwhelms families and causes a decreased capacity for them to appropriately care for and support their children/youth.

⁷ Core services provided by MCYS funded agencies. The most at risk children and youth, and the most in need of acute access to therapy are most predominantly accessing services through Ministry of Health and Long Term Care – to truly define core services, these have to include integration with hospital-based services and treatments for those children and youth most at risk.

Our survey asked families about key issues that interfered with their care and how they were impacted:



Key factors in building supporting foundations for children/youth are severely compromised due to the current structures of the child and youth mental health system and the effects to the family, and the capacity required to provide those supporting foundations.

- 81.3% of families indicate a dramatic concern for their child/youth’s future**
- 55.2% of families indicate that in general there is a dramatic negative effect/toll on their family situation**
- 38.6% of families report a dramatic financial strain being placed on the family**

If we are to truly address transformation, the burdens placed on the families must be considered and the family experience too must be transformed.

With reduced respite services, residential placements, and limited beds for hospital and in-patient treatment interventions, the burden of care often rests solely on the family. Without the proper supports and resources in place for families, they will continue to

be overwhelmed and overburdened by a system that in many cases further traumatizes and exacerbates the illnesses for which they seek treatment. Families will continue to struggle financially, their own emotional well-being will remain at risk, and the system will continue to compromise the structures of strong support systems required if children and youth are to reach their full potential.

Families are often responsible for providing support without adequate support; they make deliberate decisions to leave full-time employment to care for their child/youth due to the lack of available supports, respite, and therapy options; some families report having to be responsible for round the clock suicide watches due to the lack of available supports. The Moving on Mental Health plan does not address how it will support families who take on the bulk of their child/ youth’s mental healthcare. When identifying core services, MCYS must consider supports for families. In addition to education, awareness campaigns, and parenting classes, families need support in navigation and treatment planning as well as access to formal and informal support systems, including care teams to help decrease the burden that families currently are asked to shoulder alone.

The PCMH survey indicates that **84.1% of families were the first to identify a concern**. Supporting the family through a lens of family-centered care, must be a core priority not only of the MCYS but of **all** service providers, at all levels of care, in all Ministries.

Qualitative analysis indicates that the education and awareness that families seek is not in how to identify or recognize the need for intervention, but how to access the intervention once the need has been identified. There is a great focus currently from a number of different sources on awareness campaigns for families to identify mental health concerns; yet while building the awareness base, and potential influx of identified children and youth who need CYMH services, there is very little emphasis on helping families and professionals access or refer to appropriate family centered CYMH services.

Of the families surveyed:

55.1% of families experienced a referral to somewhere else after their initial attempt to access service

17.9% of families indicated that received no assistance at all

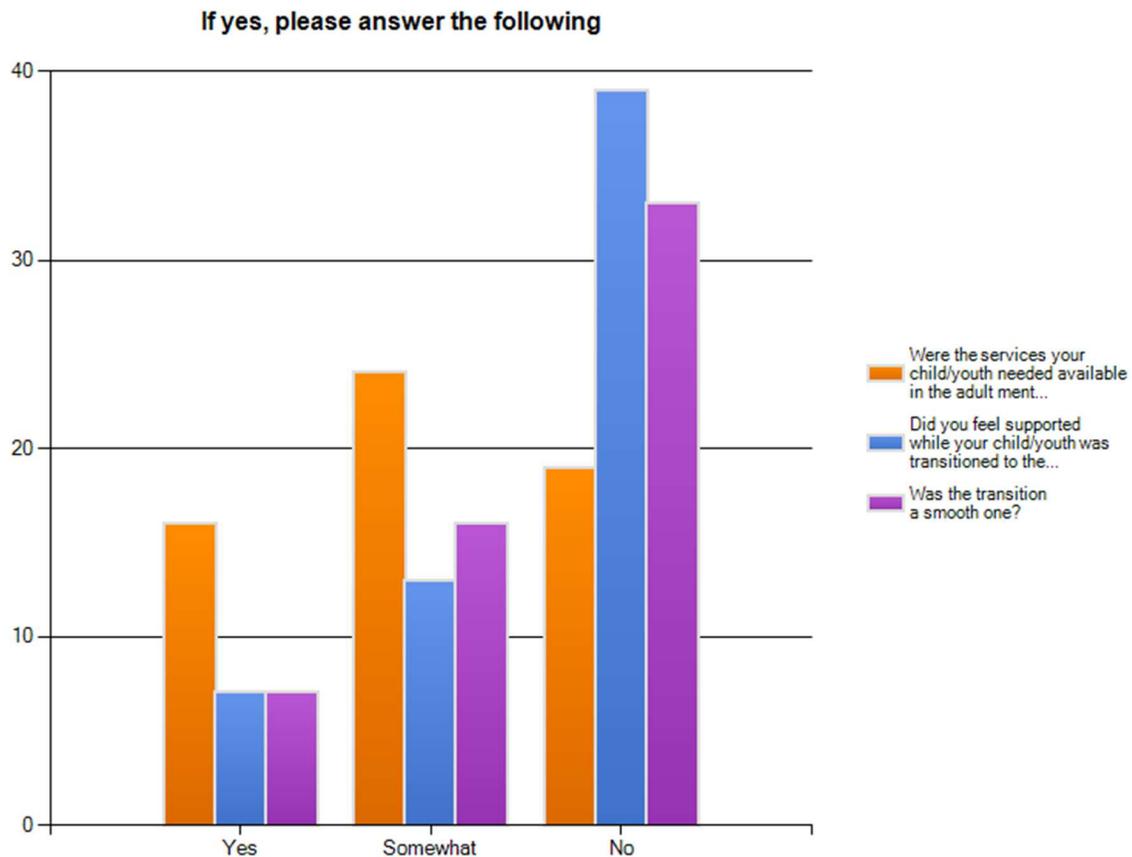
After 2 years of discussion with our pediatrician, we took our son to Emergency. The pediatrician’s comment at our next visit was “guess you’ve figured out by now that mental health is not my strong suit. Don’t think we spent 5 minutes on it in school.”

Family Member

TRANSITIONING TO THE ADULT SYSTEM

Unfortunately, current transformation plans are not taking into account the eventual need for children and youth to transition from the CYMH to adult systems. Transitions must be addressed if Moving on Mental Health envisions a system that makes sense...

While our survey did not focus on families who had experienced transitioning of children/youth to adult services, 62 respondents indicated experience transitioning from child and youth services to adult services. Although the sample size is reduced, the experiences discussed mirror recent research and consultations around transitions.



Consistently, families commented on the lack of respect for the family-youth relationship within the adult system. These comments were also reflected in the experience of families who transitioned from the child to the youth system; however, it is apparent that the complexity of transitioning become compounded and more evident when youth enter the adult system. Families are consistently expected to provide care and support in the home setting, yet they are excluded from treatment

planning receive little to no information around how to best support the treatment decisions regarding their youth.

The transition into adulthood was especially fraught with problems because most of the healthcare professionals would no longer talk to us as parents which made things quickly go from bad to worse. We were no longer allowed to make appointments for our daughter nor would they tell us when the appointments were so, of course, the result was that she did not get to her appointments because she needed us to drive her and we did not even know when they were. Then the doctors would bill her for missed appointments and we would be expected to pay the charges for the missed appointments. These charges were exorbitant and could have been avoided by simply telling us when we needed to get her there for her next appointment.

Family Member

Families are consistently being ignored as a part of the treatment plan or support system for the youth. Youth are being asked and expected to make difficult and many times ill-informed decisions about their care and treatment while in a state of crisis or resistance to treatment, even when it is identified and recognized that this is a danger to their mental wellness and often times their safety.

Consistently we hear that the lack of appropriate transition protocols and plans cause a relapse in progress. Often times a child/youth is doing well, and due to wait times, and again an inability to locate and access appropriate resources, families feel they have to start at the beginning often times having to resort once again to emergency room, or admissions to hospital to access appropriate treatment.

“When our son turned 18 he was transitioned out of the public school system/board of education and all assistance we had been provided from guidance counsellors, home based schooling, remote schooling, internet schooling, etc. all stopped and we were left on our own to determine how to help him finish his high school credits.”

Family Member

All treatment plans, regardless of the child/youth’s age, must allow for and include transition planning, and that planning and preparation must be proactive, thoughtful and timely, and must include consideration around family capacity and needs.

THE FAMILY VOICE ABOUT THE CURRENT SYSTEM AND WHAT IT WILL TAKE FOR A SYSTEM THAT MAKES SENSE

The following section summarizes the main themes drawn from the open-ended questions in the 2013 PCMH Family Input Survey. Questions underwent a preliminary analysis to determine over-arching themes and responses were subsequently coded into major categories.

1. Long wait times and access to services

There is a significant delay in diagnosis from the first experience to actual diagnosis. Participants state that this is due largely to an inability to access appropriate care, long wait times for assessments, treatment, and follow up. The average wait time for a diagnosis ranged from **4 months to 9 years**.

After a phone call to a crisis line was told the waiting list to access psychiatric services was in excess of 2 years and therefore could not be added to the list.

2. Poor System Coordination

Respondents believe that the lack of coordination between systems (ie: community-based and hospitals, mental health and education, mental health and government, and other various agencies) is fragmented and is a major barrier. Poor system coordination also ties into lack of support and information to families which makes their burden even more overwhelming.

We have yet to receive any OHIP or government funded help. We have accessed private therapy and are still waiting after 2.5 years for public help.

Families repeatedly state that the fragmented nature of the current system does not make sense and often times creates a redundancy. Poor coordination is also reducing the effectiveness of the services that are available.

3. Exclusion of Family Voice

Families report a prominent feeling during the process of finding help that they were not being taken seriously by schools, doctors, pediatricians, social workers, etc.

I had to tell my story over and over and still felt that I was not being taken seriously. Repeated assessments pointed the finger at my parenting skills. It was very frustrating to have the professionals tell me that my daughter was fine, and it taking her stabbing herself with a butcher knife for my concerns to be taken

Several report that it took a crisis such as a suicide attempt before professionals and institutions would take notice.

Families consistently reported exclusion from the assessment/treatment/ and planning care process to be a major concern in the process of finding help. Families found this concerning for a number of reasons, including the wealth of expertise that families have in regards to their children/youth that can be an asset and are instead being treated as a barrier to recovery.

Families indicate that family engagement, including inclusion in treatment and care, and respect for the role and decision-making capacity, and an understanding of the difficulties families face as the most effective form of support throughout the journey.

Peer support and family advocacy were the most effective support reported by the families who participated in the PCMH Survey throughout the journey of illness to recovery. Families state that peer supports allowed them to feel less alone, provided strategies with how to support their children/youth, and shared useful resources as well as helping them to reduce their own stigmas.

When asked the question “What about the current child and youth mental health system makes sense?” - There was only one theme that emerged from the 105 responses to this open-ended question.

What current system? I don't see it!

It does not make sense

I can find nothing to comment on, other than to say it DOESN'T make sense, on ANY level, sorry.

When asked the question “For the system of child and youth mental health services to make sense to you, what would need to be true?”

Three predominant themes emerged - which remained consistent throughout all the questions asked on the survey:

- 1. System Coordination/Integration of care between agencies, sectors, professionals, and ministries.**
- 2. Immediate access to care and treatment.**
- 3. Priority placed on Family Support and Family Engagement throughout all levels of care and system planning and implementation.**

When asked *“if you could make three immediate changes to the current system providing child and youth mental health services what would they be?”*

Themes that once again emerged and were predominant throughout all the responses

1. **Improved access to care with reduced wait times.**
2. **A formal commitment to and proactive approach to integrate and coordinated access, and processes between agencies, ministries, professionals, agencies, etc**
3. **That families be provided support as well as the children and youth, and are recognized as experts in their child/youth’s environment and care.**

THE POSITION OF FAMILIES

If our current Government wants to truly ensure that transformation results in a system “that makes sense for children and youth”, it is apparent that the focus needs to be on the consistent themes that emerged through our Province-wide consultation with families.

The transformation must not only live within, or be the responsibility of the Ministry of Child and Youth Services.

- The transformation plans be **spear-headed by the Premier of Ontario**, and that **each Ministry is held accountable to the commitment** to transform the experiences of those accessing child and youth mental health services

INTEGRATION AND COORDINATION

- Pathways to care be clearly defined and include **all** access points to assessment and treatment once a concern has been identified
- Focused and targeted education, awareness, collaboration to improve the linkages between sectors serving children and youth with mental health disorders/illnesses outside of the Ministry of Child and Youth Services
- Standardized assessments utilized regardless of sector administering them
- Comprehensive information sharing processes be established and implemented so that consistent, timely, and effective communication between service providers regardless of sector is accessed and not dependent on family
- The **Ministry of Education** will direct school boards to jointly plan community mental health services with newly established lead agencies including defining pathways to care, and ensuring all board staff are aware of and educated in the protocols, pathways to care, and committed to being engaged partners in the delivery of child and youth mental health services
- The **Ministry of Health and Long Term Care** through the Local Health Integration Networks will be directed to establish protocols that link community-based mental health services and hospital-based mental health services when a child/youth presents to hospital and/or is admitted for mental health care
- The **Ministry of Health and Long Term Care** through the Local Health Integration Networks will be directed to establish protocols that specifically address discharge planning for children/youth to transition care to community-based mental health services

- The **Ministry of Health and Long Term Care** will direct Local Health Integration Networks to jointly plan community mental health services with newly established lead agencies including defining pathways to care, and supporting education and awareness of primary care physicians in protocols and pathways to care

WAIT LISTS:

- Provincial wait list standards be established for assessment and treatment of child and youth mental health disorders/illness
- **ALL sectors** and those providing service children and youth with mental health disorders/illnesses regardless of the Ministry by which they are funded be bound by the provincial wait list standards

TRANSITIONING TO ADULT SERVICES:

- Specific processes be embedded in the transformation process and planning to take into account the transitioning from child and youth mental health services to adult services
- Standardized protocols developed to establish appropriate process and time lines for when transition planning is to begin and how it is to be implemented
- Specific discharge planning and written transition planning be provided to families prior to child’s 18th birthday

Family Expertise and Embedding Family Voice in Transformation

- In addition to the Parent and Youth Advisory Panel advising the Moving on Mental Health plan, family members and youth be embedded as core members of the Transition Team
- A Family and Youth panel be convened specific to audit and selection of Lead Agencies
- All Lead Agencies be required to participate in Family and Youth Engagement Training, and be audited regularly on fidelity to same
- Family Support Providers (navigators) be embedded throughout all levels of service delivery
- Provincial consultations be conducted with Family and Youth as pertains specifically to family and youth experience, core services, and the system framework
- Prior to implementation of Lead Agencies and Transition Plans, the Parent and Youth Advisory Panel are consulted and time allowed for potential changes to the proposed plan that will account for family and children/youth experience as advised by the panel

CONCLUSION

Bold promises and action planning is proposed in Moving on Mental Health; commitments that transformation is taking place in a partnership between Ministries and is a Government priority; establishing standardized core services, lead agencies, and clearly defined pathways to care, all commitments families can stand behind and applaud. Families do indeed applaud the MCYS, and their commitment to address issues that are not to be solved in a political cycle, and the deliberate decision to move away from discussions focused on blame or inaction to an approach of action, their commitment to a bold, and ground-breaking endeavor. The position of families is that unless this bold and ground-breaking endeavor is also taken up by the Premier it will only be a transformation in “outward appearance” or one that transforms only the administrative functions of our Ministry of Child and Youth funded services, not the experience of children,

youth, and their families. Unless the Premier, and the Ministers from the other key Ministries that need to also commit to these principles, families and children and youth will still be part of a system that does not make sense to them. The Ministry of Child and Youth Services, must be given the latitude and the support of the entire government and all of its ministries if the work they are undertaking will in totality be one that is transformative for children, youth, and families and one that families can support. Without this, families continue to believe that transformation will only have occurred and resulted in a system that makes sense for those providing the services not children, youth, and their families. Without cross-ministerial support, families fear that the Ministry of Child and Youth Services is being set up for failure, and that our journeys will be further complicated, not enhanced.

Our survey shows that the current state of mental health services is one that has reached a tipping point of crisis for families. For decades these concerns and issues have gone unaddressed and created a cycle of crisis that we have yet been able to move beyond.

It is also important to note that while this survey focused on families who are raising children and youth with mental health disorders/illnesses, and we hear consistently throughout the survey the profound negative impact our system has on families, we cannot ignore the children and youth who do not have families advocating for them. For those children and youth these issues become even more important and the negative impacts even more profound.

Our children, youth, and their families cannot afford to have this transformation effort only scratch the surface of the deficits and negative impacts the system itself creates and imposes upon children, youth and their families.

Transformation **cannot** exist only within one Ministry, and **must** be committed to and done in collaboration with all the Ministries that serve children and youth with mental health disorders/illnesses.

Should the experience of children and youth and their families not transform, and if the only transformation occurs at administrative or funding allocation levels of government, then transformation will not have been successful, families will not agree that the system is one that makes sense, and will demand better for their children and youth.

Families expect transformation by way of:

Change of composition and structure AND Change in character and condition.

For a system to make sense to those who use it, it would be one that has no funding or service boundaries. A system where families do not have to become experts in how the system works to access service, only experts on what their family and child/youth needs are. A system where family voice is respected and included in all levels of system development and implementation. A system that respects family expertise in treatment planning and implementation. A system that appreciates that for the ultimate success and impact of a child/youth’s mental health and well-being, strong family support and capacity are key factors.



Many groups of people have made serious efforts to improve service delivery children, youth, and their families with mental health problems. These groups have included policy makers, mental health professionals of all disciplines and physicians. As well, children, youth, and families have also tried but to date their voice has not been well heard. At last, finally we may be on the cusp of success! The opinions and suggestion of children, youth, and their families are paramount if we are to establish successful models of mental health service delivery for them. It is these people with lived experience who best know what they need and deserve. I applaud Parents for Children’s Mental Health for this very important initiative.

Will we as professionals, of all backgrounds take the time to finally work collaboratively, listen, and the together implement substantial changes that will allow for integrated models of service delivery that are family-centred, timely, accessible, and seamless, regardless of funding source?

Dr. Simon Davidson
Professor, Department of Psychiatry
University of Ottawa



Acknowledgments

The position paper was composed in consultation with families across the Province of Ontario, and we thank each family that took the time and made the emotional investment to have input into the transformation processes underway.

Those ensuring a return on that investment – the Steering Committee:

Sarah Cannon – Executive Director, PCMH

Laura Coughlin – PCMH Waterloo Chapter Leader

Phyllis Grant-Parker – Executive Director, Parents Lifelines of Easter Ontario, PCMH Ottawa Chapter

Kim Moran – PCMH Board Member

Michele Sparling – PCMH Board Member

Karen Wilson – PCMH Windsor Chapter Leader

Darlene Wierski-Devoe – PCMH Halton Chapter Leader, Family Engagement Co-Ordinator ROCK

We thank each of our chapters across the Province for their dedicated efforts in ensuring a true representation of family voice and the networks provided.

We thank our advisors on the paper, and the ongoing consultations with many held during the development of our paper.