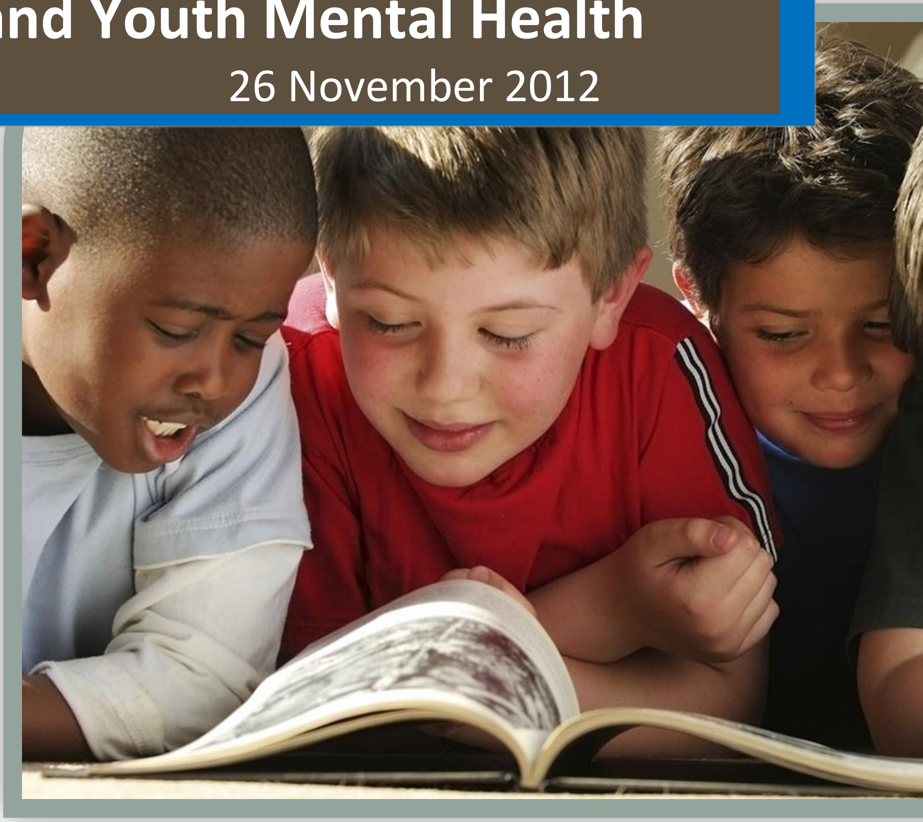
Kamloops Patient Journey Mapping Report

Child and Youth Mental Health

26 November 2012



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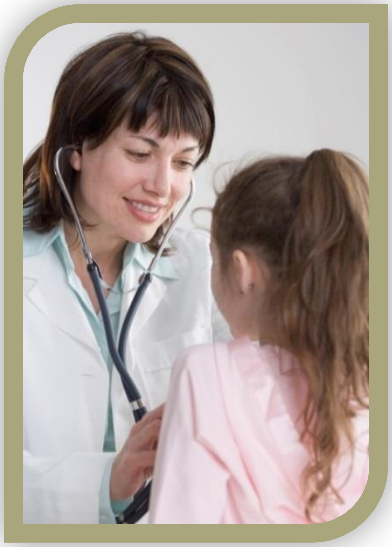
Executive Summary



Among children and youths, aged 1 - 25 years old in Canada, between 15 - 20% require professional intervention for Child and Youth Mental Health (CYMH) disorders.[1] For some, there are barriers to patient quality care.

As health care providers (HCP) and community partners, our CYMH team knew that there was room for improvement to CYMH services, so we sought an opportunity to gather input from patients themselves. Toward this aim, we organized a Patient Journey Mapping (PJM) exercise on November 26, 2012. Our PJM was a hybrid between a process map and a patient map, where the data collected came from patients and was supplemented by HCP input. We sought to capture a typical patient journey, or what happens to patients 80% of the time.

We heard common themes throughout the PJM exercise. Primarily, care comes “too little, too late,” where the health care system is built to respond reactively, rather than proactively. Approaches to patient care tend to be piecemeal, disconnected, and short term in duration. Multiple barriers prevent timely and appropriate access to care, such as significant waiting lists to obtain CYMH services. There is a strong need for greater collaboration, support, and education for patients, families, and providers.

This report presents the successes, challenges, and opportunities of a system in need of improvement.

In conversations throughout the PJM exercise, five broad areas for improvement emerged:

- Communication
- Resources
- Policies and Protocols
- Education and Awareness
- Quality Improvement Measurements

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[1] Waddell C, Offord D, Shepard C et al. Child psychiatric epidemiology and Canadian public policy-making: the state of the science and art of the possible. *Can J Psychiatry* (2002): 47825-832.

In light of the identified successes and challenges, some tremendous opportunities emerged. The top five highest ranked opportunities for improvement as identified by our PJM patient experts and providers were:

- Earlier and coordinated CYMH intervention
- Improved communication among CYMH organizations and providers about CYMH resources
- Robust support for families, shift from child-focused to family-focused
- A consistent case manager to coordinate CYMH patient care
- A health passport for CYMH

In response, this report includes recommendations and next steps for the short and long term.

Moving forward, we will actively disseminate our PJM findings with the Province of British Columbia and among key stakeholders, such as General Practitioners (GP), Specialists (SP), School District 73 (SD73), and other community partners and organizations.

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Background

CYMH issues are found globally[2] and are consistent across Canada. Among young people aged 1 - 25 years old, 15 - 20% of these require professional intervention. Of these patients, approximately 60 - 70% can be managed effectively in primary care. Among all types of CYMH disorders, Anxiety ranks highest at 10%, Depression at 5%, and Attention Deficit Hyperactivity Disorder (ADHD) at approximately 4%.[3]

Our decision to conduct a PJM grew out of conversations held among local Kamloops CYMH professionals as our team prepared to develop a CYMH learning module for GPs and Family Physicians (FP) through the Practice Support Program (PSP). As HCPs and community partners, we knew there was room for improvement, but we sought an opportunity to gather input from patients themselves. Toward this aim, we organized a PJM event.

Patient Journey Mapping is an exercise done to understand how patients experience health care services. Since patients are the only people who experience all health care services first hand, they have a highly relevant perspective on the way services work, and how these services can be improved. HCPs contribute to the exercise by sharing their perspective on the delivery of health care services.

Our PJM took place at the Tournament Capital Centre at 910 McGill Rd. in Kamloops, BC between 9am and 3pm on Monday, November 26, 2012, involving 34 participants.

Aim Statement

The PJM process helps healthcare providers understand the patient perspective on how patients proceed through the care delivery system. It initiates conversations that must identify constraints, bottlenecks, duplication of services, and unnecessary steps. From a quality improvement perspective, successful navigation of patients through the access, flow, and transition of their care is critical to good health outcomes.

On November 26, 2012, our team mapped the journey of children and youth with mental health disorders from the perspective of the patient and his/her family in Kamloops, BC from:

1. Onset of signs and symptoms or feeling unwell to initial diagnosis;

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[2] World Health Organization (2003). Caring for Children and adolescents with mental disorders. Setting WHO directions. http://www.who.int/mental_health/media/en/785.pdf

[3] Waddell C, Offord D, Shepard C et al. Child psychiatric epidemiology and Canadian public policy-making: the state of the science and art of the possible. *Can J Psychiatry* (2002): 47825-832.

2. Initial diagnosis to first treatment plan;
3. First treatment plan to present day.

We aimed to capture the patient's perspective related to the initial and continued referral and communication processes among all stakeholders involved in the patient's care. In doing so, this PJM addressed successes, challenges, and gaps related to access, continuity of care, support services, transitions in care, and communication.

With the information and knowledge gained from the PJM process, we identified five (5) broad areas to improve patient care and stakeholder experience. These were communication, resources, policies and protocols, education and awareness, and quality improvement measurements.

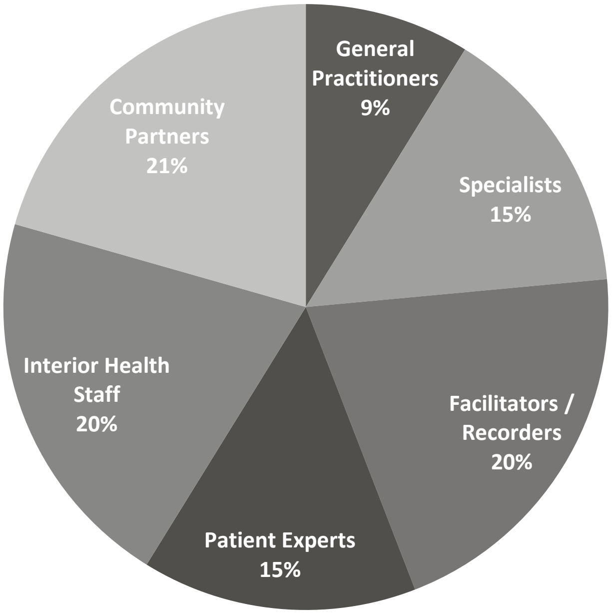
For consideration:

- Identify available resources to conduct a mapping process
- Identify key stakeholders
- Commit to a full day
- Create a collective understanding of PJM purpose and intent
- Create an environment and space that is respectful and safe for all
- Manage follow up effectively
- Report outcomes back to stakeholders
- Share PJM learning with others

Participant Profile

This PJM brought together patient experts, physicians, Interior Health Authority (IHA) staff, and community partners. Community partners included representatives from the Ministry of Children and Family Development (MCFD)/CYMH, SD73, the Phoenix Centre, and Youth Forensic Psychiatric Services.

A total of 34 people participated. In addition to five (5) facilitators and two (2) recorders, there were five (5) patient experts and/or patients' parents, seven (7) Interior Health Authority staff, seven (7) community partners, and eight (8) physicians. Among physicians, three (3) were general practitioners (GPs), and five (5) were specialists (SPs), including three (3) child psychiatrists, and two (2) pediatricians.



Methodology

Our mapping methodology was a hybrid model where we incorporated aspects of process mapping and patient journey mapping. Health care providers offered their perspectives, but the patient experts' stories formed the centerpiece of the data collected.

It is important to be clear about our inclusion criteria for our patient population. We only included patients who are attached to a GP. We made this decision in part because we were aware that unattached patients experience an additional set of challenges navigating the health care system. We aimed to invite at least one Aboriginal patient. Although we were unsuccessful at Aboriginal patient recruitment, an Aboriginal stakeholder participated during the PJM event. Although age was not a limiting factor when selecting our patient population, only the parents of child patients attended the PJM event, with the exception of one teenaged youth patient who attended with a parent.

Traditional PJMs are structured around one large group, where everyone listens to one patient speak at a time. Given the sensitive nature of our population as children and youths, we modified the traditional PJM process to accommodate the privacy of our patients and to ensure a safe space for everyone to share their journeys. Our modifications also enabled us to accommodate a large number of stakeholders who were keenly interested in participating on this day.

We modified the PJM process as follows. The room was arranged into four tables and each table centered on one patient's experience. At three of the tables, the parent provided the patient perspective, while at the fourth table, both the parent and the teenaged youth patient participated. Each table included a facilitator, plus one HCP and one community partner from each key stakeholder organization. Each table included eight (8) or nine (9) participants in total.

The day opened at 9am with a welcome, introductions, and review of the PJM purpose. See Appendix A.

The morning was spent creating the map, while the afternoon was spent analyzing the map. While creating the map, participants were guided by the following three touch points:

1. From onset of signs & symptoms or feeling unwell to initial diagnosis

2. From diagnosis to first treatment plan

3. From first treatment plan to present day

It is important to note that the patient's journey often begins before the first clinical encounter, with his/her own undiagnosed experience with mental health issues and behaviors. We drafted our first touch point with this perspective in mind.

As patients shared their journeys at each table, we collectively created a draft map on sticky notes, while a graphic artist captured the journey visually by drawing a map. See Appendix A.

Once the map was completed, we analyzed the map at each table with a focus on successes, challenges, and opportunities. Collectively, we shared our ideas. Thereafter, we voted publicly on the list of opportunities to determine the participants' top opportunities through a group decision-making process known as "dotmocracy."

With the dotmocracy process, participants voted on the list of opportunities by placing a limited number of dots beside their most favored opportunities. Each patient and provider received six dots and was instructed to place no more than two dots per opportunity. Facilitators and recorders did not vote. The day closed at 3pm.

Five key opportunities emerged and are reported on page 16. The original dotmocracy data are included in Appendix B.

The Patient Journey Map

Our PJM exercise captured information about the journey of a typical CYMH patient in two forms: words and images. It is important to note that the journeys of each of our four patients are highly individualized and our patient journey map aimed to capture what happens to patients 80% of the time.

PJM in words

The following is a narrative of the typical patient journey collected from our PJM exercise. Information in brackets indicates the wait times a patient might experience in the course of diagnosis and treatment for CYMH disorders.

> *At a very early age, Jane showed signs of behavioral issues, including extreme tantrums. Jane's parents knew something was wrong, but found no support for Jane between the ages of two through six. Jane entered the school system. She was bullied, labeled, developed no friendships, could not follow instructions, and was disruptive in the classroom. A teacher approached Jane's parents, developed an Individualized Education Plan (IEP), and enrolled Jane in learning assistance classes and behavior intervention. Jane's parents sought advice from the internet and advice from their GP, who referred Jane to a pediatrician (6 month wait list). The pediatrician provided multiple diagnoses and put Jane on multiple medications. Jane was referred to MCFD-CYMH (1+ year wait list).*
>
> *In the interim, Jane was admitted to the emergency room (ER) for aggressive behavior at daycare, which prompted a referral to Parkview for assessment. CYMH referred Jane to a psychiatrist in Vancouver at the BC Children's Hospital, where Jane was diagnosed multiple*

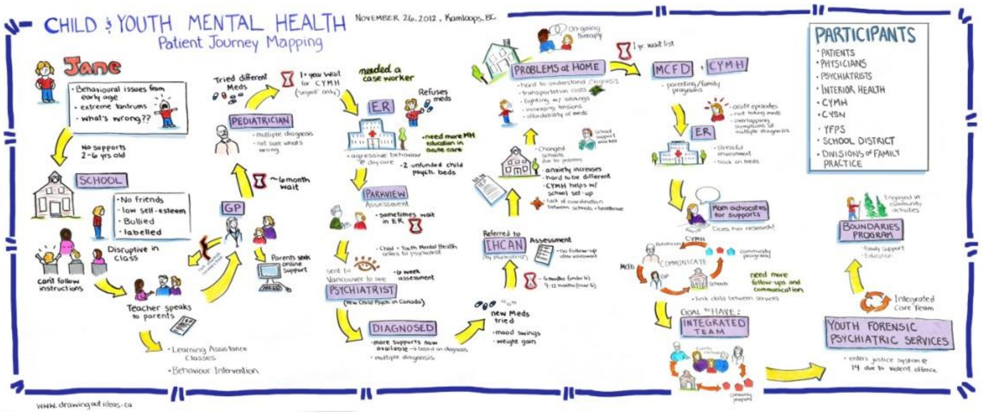
times. Jane's final diagnosis availed a broader selection of support services. Based on the new diagnosis, Jane trialed the new medications. These medications produced mood swings and weight gain. Jane was referred for an Interior Health Children's Assessment Network (IHCAN) assessment (9 - 12 months wait list) and thereafter received a new IEP.

Meanwhile, due to problems at school, Jane changed schools with CYMH's assistance, which increased her anxiety and contributed to problems at home. A school support worker was available to Jane, but there was an absence of coordination between the schools and the health care system. Jane participated in ongoing therapy to understand her diagnosis, but continued to fight with her siblings. Her parents struggled with the cost of medications, transportation, and the stress. Eventually, MCFD-CYMH became a source of additional support for a parenting and family program (1 year wait list). Meanwhile, Jane stopped taking her medications and experienced acute episodes, which prompted another visit to the ER. Jane's parents gathered research and advocated for further support among MCFD-CYMH, the pediatrician, the GP, schools, and community programs.

Today, Jane is 14. This last year, she entered the justice system and Youth Forensic Psychiatric Services after a violent offence. Only after the legal system became involved did Jane receive an integrated care team and exposure to the Boundaries Program, with a focus on community activities.

PJM in images

A graphic artist captured the typical patient journey in images. A copy of the map is located below, while a larger version is included in Appendix A.



Findings

Successes

The following information captures the responses provided by patient experts and other participants when asked: What are the successes?

From onset of signs & symptoms

IHCAN provides pieces of the puzzle, but not necessarily the whole picture, e.g. identified diagnoses, but not the supports necessary

From diagnosis to first treatment plan

Consistent outreach worker available to patients after hours

CYMH attends patient's appointments

School offers behavioral intervention classes

IEP on the right path

From first treatment plan to present day

Experiences like the PJM, listening to patient voices

When medication works (or the period it works)

BC Children's Hospital was able to provide parents with valuable skills to support child

Having the team come together on the same page, but this did not happen until the legal system got involved

Additional Successes

- Consistent care from a longitudinal, local, stable team
- Consistent care from pediatrician
- Consistent community support, e.g. bus driver, teachers
- Practical support and education from various programs, e.g. CYMH, Forensics, Boundaries Program, school, sign language
- Family stress reduced from the addition of an extra child psychiatrist to Kamloops, accessible by text/cell with a quick response
- Development of an ER Care Plan for ER staff
- Ability to feel comfortable asking questions
- Access to respite and respite funding to support the patient and their family

Challenges

The following information captures the responses provided by patient experts and other participants when asked: What are the challenges?

Inadequate capacity, services, and access to quality care

- Difficult to access medical services due to capacity issues. Long wait lists (up to one month for GP, three to six months for pediatrician, nine to twelve months for CYMH, and years before child psychiatry). In one instance, it took two years before the patient could access CYMH services. Often times, the patient can only access services when he/she is in a crisis situation.
- Lack of acute care inpatient beds - only two child psychiatric beds at the Royal Inland Hospital (RIH). For a regional hospital serving a large catchment area, these two beds are inadequate as children are held in various emergency settings until a bed becomes vacant. In crises, physicians recommend hospitalization but are uncomfortable using local community facilities for acute suicidal, homicidal, or psychotic children. These patients often are under involuntary committal when they are transported to ER and the system is bound to accommodate. Since there are only two dedicated child psychiatric beds, patients can be kept waiting days in the ER or until adequate resources and supports are in place to support the patient and family in the community. In some cases, when patients are admitted to the pediatric floor in a non-psychiatric bed, there is a lack of physical space for privacy for the patients and their families to discuss confidential issues, particularly for depressed and suicidal teens because quarters are shared with other patients admitted with non-psychiatric diagnoses.
- Practical challenges related to access for families include: the cost of public transportation for low income families, inconvenient bus schedules that do not align with the various offices and agencies, no designated supports for accommodations for out of town families, and lack of access to CYMH community supports and resources in rural communities.
- Substantial lag time from presentation to diagnoses. Can sometimes take up to four years for a correct diagnosis. There are frequent multiple overlapping diagnoses, misdiagnoses, and misunderstandings of child/youth symptoms, where various treatments are tried before an actual diagnosis. The involvement of multiple agencies and differing specialties during the initial management of the patient can be uncoordinated. There are no longitudinal, consistent care plans for patients among different agencies and physicians due to uncoordinated communications among these silos of care.
- Barriers for families to access appropriate treatments, e.g. the medications for best management of patient's conditions due to the financial costs of some medications and the prescriptive requirements of Pharmacare to "trial" first line medications.

- Lack of psychology services both in terms of available child psychologists and the costs to see them since most work out of the private system and are expensive. In the majority of situations, patients are unable to access psychological services when needed and there are long wait lists to see a psychologist.
- Providers have difficulty knowing how and to whom they can advocate for their patients due to the different agencies involved, e.g. MH versus MCFD.
- Lack of specific and appropriate training for frontline staff who serve patients and their families with MH disorders especially in the acute care settings, e.g. ER staff, nursing staff on the pediatric wards.
- Lack of standards of care for the CYMH population.

Lack of coordinated care and systems

- Lack of consistency and follow-through with multi-disciplinary care plans when created by one organization with the patient and family due to interference by other organizations, e.g. MCFD, School Board, physicians. Present systems with temporary programs and contract agreements are not built for the consistent, longitudinal support and care required for patients and their families.
- Inability to link data together across programs and the lack of communication across programs leads to inconsistent care planning. This sometimes results in a doubling up of care plans, and often times results in a lack of continuity in care management.
- Lack of case managers. Note: Today, there are three case managers at Parkview, with particular success at treating complex disorders.
- Inadequate school services, whereby patient had to transfer multiple schools in order to access different services.
- Inadequate referrals to out of town services, e.g. BC Children’s Hospital and a lack of feedback as to the assessment and recommended care plan for follow-up management.
- Difficult to access acute care beds. BC Bedline is unable to locate beds in most cases.
- Differing Ministry mandates, e.g. MCFD’s mandate for child protection can intimidate families seeking care for their child/youth.
- Inadequate sharing of patient information due to privacy legislation that blocks information among providers and produces silos of care.
- Patient expert commented that he/she felt he/she was “falling in between the cracks.”
- Patient expert had difficulty understanding how to access care in a system with multiple HCPs that are not connected and integrated with each other.
- Patient expert experienced a disorganized, piecemeal approach to care with lack of coordination and lack of an integrated model for care.

Barriers to effective patient-provider communication

- Lack of shared information. This required the patient to repeat the same story of his/her mental health challenges to different caregivers and multiple service providers.
- Lack of a comprehensive family approach and family support.
- Lack of patient-centred care.
- Lack of acknowledgement for the patient and parents as experts in their own experiences.
- Difficult to understand multiple systems and agencies, e.g. access, criteria for funding.
- Lack of a standardized system of cooperation from the school system regarding student mental health issues, e.g. teacher not required to read patient's report or contribute to a questionnaire about his/her experience with the student.
- Difficult for GPs to understand and/or access the various MH and CYMH program areas because there is no local resource directory.
- Patient expert often felt that he/she was not heard and the system was unresponsive to his/her needs. In particular, in the ER department, families felt blamed for the acute crisis rather than understood by the HCPs.

Financial impacts

- Appropriate medications can be expensive and unaffordable.
- Necessary services can be expensive and unaffordable because they are not publicly funded, e.g. occupational therapists, psychologists.
- Patient expert commented that he/she found the process to access funding for services and the need to prove "poverty" a humiliating one.

Stigma

- Reluctance to seek support because some diagnoses are shame based and lead to stigmatization, e.g. FASD.
- Reluctance to seek support because of fears of children being taken away from their families through child protection services.

Five Areas for Improvement

Consistent with our aim statement, we identified five areas to improve patient care and stakeholder experience. The five areas for improvement were communication, resources, policies and protocols, education and awareness, and quality improvement measurements.

It is important to note that communication is often the least expensive but most critical. Communication also can be the most difficult change among different jurisdictions.

Communication

- Increase communications between the differing silos of care to offer more of a multi-disciplinary team approach to care, including SPs, GPs, MCFD, acute care staff, and CYMH community providers.
- Improve efficiency of flow of information to patients, from patients, and amongst all providers involved with the case.
- Improve how evidence-based care and treatment plans are shared with patients and their supportive HCPs to provide consistency and continuity of care.

Resources

- Increase funding for both the quantity and quality of local inpatient care. For example, there is a need to increase the number of funded child psychiatric beds and to create a “home-like” environment rather than a hospital environment.
- Increase funding for CYMH community resources.
- Improve efficient use of funding and services, e.g. avoid duplication of treatment plans among various organizations.
- Support the training and funding of child psychiatrists in Canada.
- Increase funding supports for families especially the vulnerable, marginalized, low income, and isolated in order to gain access to services, e.g. transportation, medication, accommodations, respite, and necessary treatment and counseling services.

Policies and Protocols

- Remove the multiple, often-conflicting mandates from different program areas, with an aim toward consistent, cross-organizational guidelines for care.
- Remove or reduce the impact of privacy issues in order to coordinate better patient care across different jurisdictions.

Education and Awareness

- Increase patient self-management, health literacy, and advocacy.
- Increase provider education among GPs, teachers, school counselors, community support workers, acute care staff, and registered nurses in ER and on the wards.

Quality Improvement Measurements

- Increase the use of quality improvement measurements for patient care, as is evidenced by the lack of accountability to follow up and follow through with patient care plans and treatment.
- Establish a triple aim strategy for CYMH, with emphasis on measurements that concurrently improve patient and family experiences with care, improve population health, at the best cost possible.

Five Key Opportunities

The following information captures the five highest ranked opportunities as identified by both patient experts and other participants when asked: What are the most important opportunities?

Earlier and coordinated CYMH intervention

- Earlier identification and coordination of support, including a CYMH program focused on earlier support and education for parents and families.
- Patient experts indicated that it should not take late-stage involvement with the legal/forensic system before patients receive quality, coordinated care.

Improved communication among CYMH organizations and providers about CYMH resources

- CYMH HCPs should team with community partners and SD73 to focus on self-regulation work in the classroom, ideally starting in daycare/preschool.
- Better information sharing regarding local community supports and services to all the stakeholders including GPs, SPs, and acute care HCPs.

Robust support for families, shift from child-focused to family-focused

- More services to ensure quicker access to CYMH services and family counseling.
- More parental behavioral support.
- More financial support to vulnerable families.
- A team approach to patient care with coordinated case conferences to increase efficiency and effectiveness of care delivery to patients and families.

A consistent case manager to coordinate CYMH patient care

- A liaison to help patients navigate the system, ensure consistency, and to improve communication among HCPs.

A health passport for CYMH

- A tool to prevent miscommunication, to create seamless communications, and to avoid the need for patients to tell their story repeatedly to different care providers.
- Examples of health passports currently used in BC for other programs are a Pregnancy Passport offered through Perinatal Services BC, with a password-encrypted website accessible to both patients and providers.

- Examples of alternative tools in other jurisdictions include a password-encrypted health care card used in France, or a personal, electronic USB port.

Recommendations/Next Steps

Short term goals

- Plan a local CYMH Strategic Planning Meeting to provide systems-level solutions among decision makers focused on the PJM findings, including earlier intervention, coordinated care, and collaboration.
- Encourage community support for children and families, such as volunteer or foster grandparents.
- Work with Nurse Family Partnership for early support of mothers at risk,[4] such as pregnancy outreach programs (e.g. Baby's Head Start), peer-supported programs (e.g. Family Tree), and MCFD-funded programs (e.g. Infant Development Program).
- Support, educate, and increase the confidence of primary care physicians in dealing with CYMH disorders through programs such as the PSP CYMH module, plus increasing awareness of all available community and Provincial resources, e.g. Kelty Center in Vancouver.
- Create a local multi-disciplinary clinic for attachment, trauma, and neglect.
- Work with patients on multidisciplinary teams, e.g. psychiatrists, occupational therapists, social workers, mental health staff, GPs, pediatricians, child psychiatrists, and child psychologists.
- Ensure that HCPs (registered nurses in hospital wards, ER, and community, as well as school counselors, mental health workers) possess the necessary skills in child psychiatry or basic training in pediatrics, psychiatry, and appropriate behavioral management as well as on-the-job training supports.
- Review the MCFD barriers to access and care, particularly the compelling mandate for child protection since families can be afraid to report difficulties due to stigma and fear of children being taken away.
- Review the efficiency of utilization of child psychiatric services through MCFD, MH, and private offices, and facilitate the best access points.
- Encourage better communication tools among all organizations with a stake in the patient's health, including SD73, teachers, counselors, local and provincial hospital staff, mental health providers, psychiatrists, pediatricians, forensic services, family support

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[4] McCain MN, Mustard JF. *Reversing the real brain drain: Early years study*. Toronto, ON: The Canadian Institute for Advanced Research, 1999. McCain MN, Mustard JF, Shanker S. *Early years study 2: Putting science into action*. Toronto, ON: Council for Early Child Development, 2007. See also: http://earlyyearsstudy.ca/

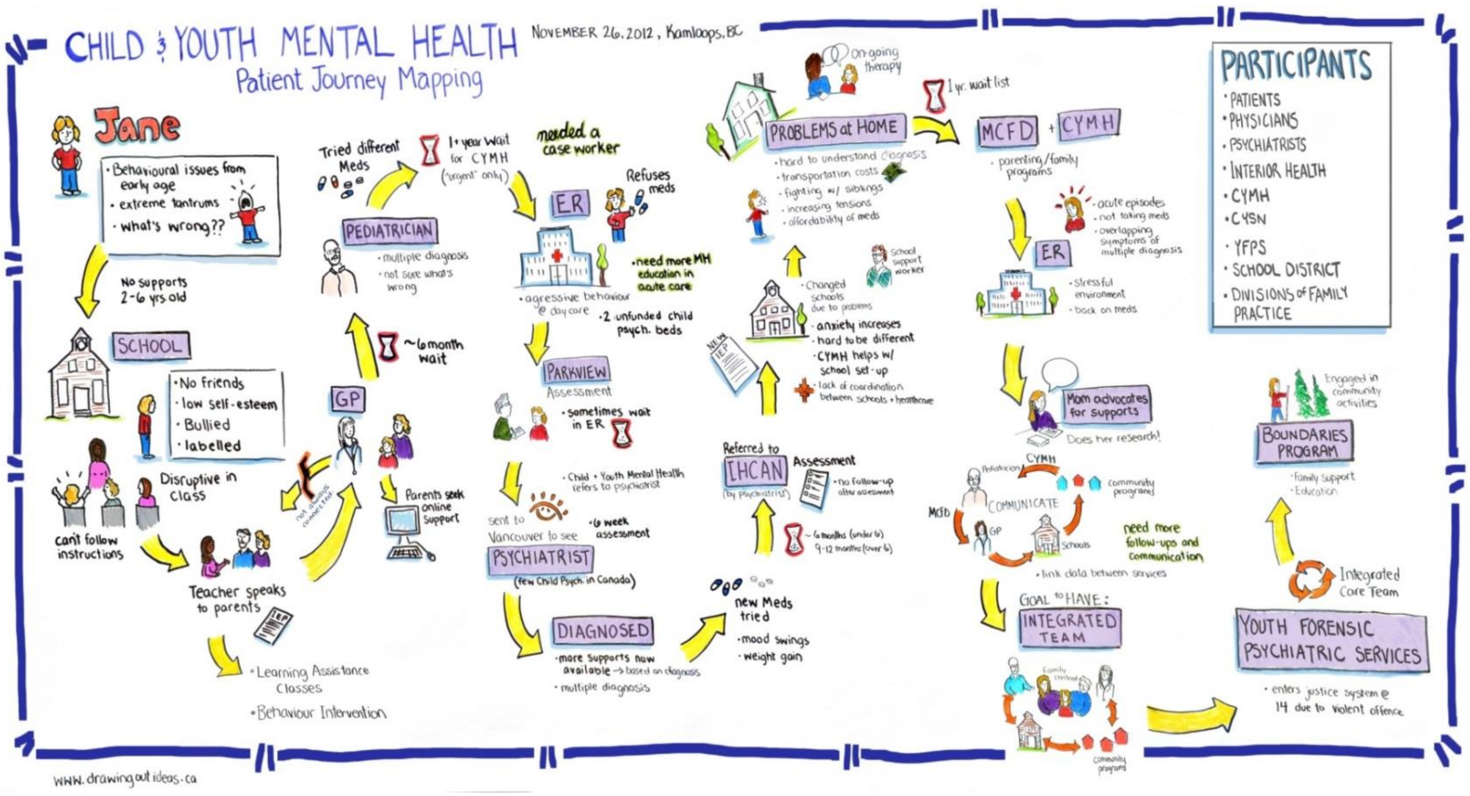
teams, dedicated programs, addiction services, and especially to the FPs who should be the quarterback for the family and the patient navigating this system of care.

Recommendations/Next Steps

Long term goals

- Ensure there is adequate recruitment, training, distribution, and support for child psychiatrists in Canada compared to one child psychiatrist to 90 - 150 cases in Galway, Ireland.
- Increase the number of funded CYMH acute hospital beds, preferably close to the hospital in a family-centered location with some beds reserved in the hospital for children and youth committed to a designated facility under the Mental Health Act (presently there are only two unfunded beds in RIH).
- Create business case for establishing an early intervention team that would provide coordinated integrated services to children and youth facing mental health challenges
- Explore the utility of Primary Case Coordinators or Patient Navigators to access and support transition among services and especially around transitions from youth to adult services.
- Create a seamless communication platform for all HCPs and stakeholders to communicate effectively about care plans, individual visit action plans, and medication changes.
- Establish regular care conferences around patient care with patient, family, physicians, schools, IHA, and MCFD mental health services along with SD services and any other stakeholders, e.g. Forensics, Aboriginal Health to enhance coordination of services.
- Develop a compendium of referral services, community services available to physicians, patients and their families.
- Facilitate educational resources for the public.
- Encourage and support the creation of peer support groups.
- Establish CYMH clinical and referral pathways for IHA.
- Advocate for the removal of multiple, often conflicting mandates from different program areas, with an aim toward consistent, cross-organizational guidelines for care.
- Reduce barriers to patient access to MH services by advocating for the inclusion of CYMH under the Ministry of Health portfolio and/or advocating for less stringent criteria for patients to access outpatient MCFD services and/or advocating for a shared care approach among MCFD, the Ministry of Health, and the Health Authorities.
- Provide supports and consistency of system delivery to ensure child and youth with mental health issues can ttransition to adult services, not just from a medical perspective but also in vocational training, counseling, and housing supports.

Appendix A: The Maps


CHILD & YOUTH MENTAL HEALTH
Patient Journey Mapping
NOVEMBER 26, 2012, Kamloops, BC
Jane
· Behavioural issues from early age
· extreme tantrums
· what's wrong??
No supports 2-6 yrs old
SCHOOL
· No friends
· low self-esteem
· Bullied
· labelled
Disruptive in class
can't follow instructions
Teacher speaks to parents
IEP
· Learning Assistance Classes
· Behaviour Intervention
GP
not always connected
Parents seek online support
~6 month wait
PEDIATRICIAN
· multiple diagnosis
· not sure what's wrong
Tried different Meds
1+ year wait for CYMH ("urgent" only)
needed a case worker
ER
Refuses meds
· agressive behaviour @ day care
· need more MH education in acute care
· 2 unfunded child psych. beds
PARKVIEW Assessment
· sometimes wait in ER
· Child + Youth Mental Health refers to psychiatrist
sent to Vancouver to see
· 6 week assessment
PSYCHIATRIST
(few Child Psych. in Canada)
DIAGNOSED
· more supports now available → based on diagnosis
· multiple diagnosis
new Meds tried
· mood swings
· weight gain
Referred to IHCAN (by psychiatrist)
Assessment
· no follow-up after assessment
~6 months (under 6)
9-12 months (over 6)
NEW IEP
· Changed schools due to problems
School support worker
· anxiety increases
· hard to be different
· CYMH helps w/ school set-up
· lack of coordination between schools + healthcare
On-going therapy
PROBLEMS at HOME
· hard to understand diagnosis
· transportation costs
· fighting w/ siblings
· increasing tensions
· affordability of meds
1 yr. wait list
MCFD + CYMH
· parenting/family programs
· acute episodes
· not taking meds
· overlapping symptoms of multiple diagnosis
ER
· Stressful environment
· back on meds
Mom advocates for supports
Does her research!
CYMH
Pediatrician
community programs
COMMUNICATE
MCFD
GP
Schools
need more follow-ups and communication
· link data between services
GOAL to HAVE:
INTEGRATED TEAM
Family centred
community programs
PARTICIPANTS
· PATIENTS
· PHYSICIANS
· PSYCHIATRISTS
· INTERIOR HEALTH
· CYMH
· CYSN
· YFPS
· SCHOOL DISTRICT
· DIVISIONS of FAMILY PRACTICE
Engaged in community activities
BOUNDARIES PROGRAM
· Family support
· Education
Integrated Core Team
YOUTH FORENSIC PSYCHIATRIC SERVICES
· enters justice system @ 14 due to violent offence
www.drawingoutideas.ca

Appendix B: Dotmocracy Data for All Identified Opportunities*

*These data reflect the primary source language captured during the PJM. As a result, there is some thematic overlap among ideas.

All Identified Opportunities*	# of Patient Votes	# of Provider Votes	All Votes	% of all Votes
Earlier and coordinated intervention	**4**	**22**	**26**	**17%**
Robust support for families, shift from child-focused to family-focused	**3**	**11**	**14**	**9%**
Have a consistent case manager to coordinate care	**3**	**10**	**13**	**8.40%**
A health passport	**1**	**11**	**12**	**7.70%**
Better communication re: resources and current resources	**0**	**10**	**10**	**6.50%**
Create an appropriate treatment environment – (e.g. "home" like setting, not formal, psych beds locate in home setting rather than hospital setting, family and child friendly, close to hospital but not necessarily in the hospital)	1	7	8	5.50%
Transition to adult services, not just from a medical perspective; vocation training, counseling, housing	2	6	8	5.50%
Develop a support system for the single parents, foster program, or foster grandparents	3	3	6	3.90%
Coordinated case conferences		6	6	3.90%
Advocacy	1	4	5	3.20%
Better communication with parents about appropriate and current resources (e.g. CCRR)	2	3	5	3.20%
Support for teachers and school counselors re: behaviours	1	3	4	2.60%
Legal system should not be required for good care	4		4	2.60%
Better communication and collaboration between pediatrician, GP, CYMH/MCFD	1	2	3	1.90%
Education for family doctors (e.g. PSP)	0	3	3	1.90%
Culturally sensitive and safe services	0	3	3	1.90%
ICMs – more of these, just talk, relationship-based care is important – face to face communication, rather than email and report-to-report	0	3	3	1.90%
Longitudinal care and support/frontline staff understand the big picture of the patient	1	1	2	1.30%
Information sharing between all agencies/services involved with patient	0	2	2	1.30%
Primary case care coordinator compiles information to distribute to all service provider, closes the loop	1	1	2	1.30%
Consistent approach	1	1	2	1.30%
Create opportunities for youth to share stories (e.g. with families, other youth, HCPs, system planners)	1	1	2	1.30%
Help with logistics (e.g. getting to appointments, prescription pick-up, one stop shop, e.g. youth King St.)	0	2	2	1.30%
Incentives for physicians to go to rural areas and support to retain them	0	2	2	1.30%
Forum for all organisations to work together (e.g. SD, community partners) as a team for the patient	0	1	1	0.60%
Service coordination (address needs and functions)	0	1	1	0.60%
A central referral point or call centre for everyone to learn more about community services	0	1	1	0.60%
Written reports to have an executive summary or highlighted recommendations	0	1	1	0.60%
Family and Youth education (e.g. side effects of medications, self-management strategies, choices)	0	1	1	0.60%
More consultation with families (e.g. on location of a facility)	0	1	1	0.60%
Identify some long term goals for addictions, mental health	0	1	1	0.60%
De-stigmatize CYMH services and be more proactive with early prevention	0	1	1	0.60%
Timing for relationships (e.g. social worker)	0	0	0	0%
Working as a broad team to provide care for patient				
More of a focus on community facilities, home environment rather than hospital environment				
More appropriate in-patient care (local)				
Better communication and collaboration among providers				
More appropriate inpatient care locally, rather than BC Children's hospital				
A primary case coordinator to close the loop				
Education at many levels, public education e.g. issues of child protection				
Advocacy and opportunities for outreach				
Clinical and referral pathways for Interior Health				
Linking with school, community services				
Public education and peer support, use the wisdom of the family				
More sharing, less fear around privacy issues, sharing information across programs				
Education for staff (e.g. information sharing)				
Totals	**30**	**125**	**155**	**100%**

Appendix C: Key Contacts

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Glossary of Terms

ADHD	Attention Deficit Hyperactivity Disorder
CCRR	Child Care Information and Resource and Referral
CYMH	Child and Youth Mental Health
DFP	Divisions of Family Practice
ER	Emergency Room
FP	Family Practitioner
GP	General Practitioner
HCP	Health Care Provider
ICM	Integrated Case Management
IEP	Individualized Education Plan/Program
IHA	Interior Health Authority
IHCAN	Interior Health Children's Assessment Network
MCFD	Ministry of Children and Family Development
MH	Mental Health
PJM	Patient Journey Mapping
PSP	Practice Support Program
RIH	Royal Inland Hospital, Kamloops, BC
SD73	School District 73, Kamloops, BC
SP	Specialist Physician