VCH Community Engagement

Child & Youth Mental Health and Substance Use Redesign

Interim Stakeholder Engagement Report

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Background

Vancouver Coastal Health is seeking to improve the Child and Youth Mental Health and Substance Use system of care in Vancouver. To do this, they are embarking on a process to develop an evidenced based child & youth mental health and substance use strategic framework with the goal of creating a system that provides streamlined and equitable service for children, youth and their families. This strategy would bring together child and youth mental health and substance use services as well as VCH Public Health services to deliver health promotion and services along a continuum that matches service intensity to changing health needs. A critical component of this process is assessing the current services through the lens of individuals that are directly affected by the system.

The CYMHSU project leadership approached VCH's Community Engagement Team for support in bringing the voice of stakeholders into the planning process. Stakeholders included youth aged 0-12, 13-18 and 19-24 who had accessed CYMHSU care, their families, service providers in the community, contracted agencies, and VCH staff. They also wanted to hear from youth and families across a range of demographics and experience; from those with mild to moderate MHSU issues, to those with more serious MHSU issues.

It was decided that engagement would take place in two phases. The purpose of the first phase would be to:

a) Inform stakeholders about the VCH CYMHSU strategy planning process
b) Hear stakeholder ideas for change to improve the system, with a focus on three key areas: access, navigation and transitions

Input from this first phase of engagement would be considered along with evidence from the literature and VCH utilization data to generate a list of possible initiatives to undertake to improve the CYMHSU system. The second phase of engagement would then involve stakeholders in a process to choose priorities for action.

To initiate the first phase of engagement two open forums were held in March, 2017. One forum was for service providers working with children, youth and families who may experience mental health and substance use issues. The other forum was for families and youth who have experience with the mental health and substance use system. An additional focus group was also conducted with physicians from BC Children's Hospital and a telephone interview was conducted with a service provider who was unable to attend the forum. This interim report summarizes what was heard from participants in these forums and conversations.

A separate youth engagement process is planned for May 2017 in addition to two forums for VCH CYMHSU staff. Addendum reports summarizing input from the youth engagement process will follow.

Who Did We Hear From?

A total of 66 people participated in the forums, focus groups and interview captured in this report:

- 50 service providers from 25 different agencies across Vancouver attended the forums
- 4 physicians participated in a focus group
- 12 people attended the forum for families and youth. Two were youth who access care through VCH CYMHSU.

Limitations:

Thirty-four people, including six youth were registered to attend the family and youth forum. The high number of no-shows may in part have been due to inclement weather the day of the forum. The family members and youth who did attend came from a broad diversity of ethno-cultural groups and experiences. However, the low number of participants supports the need for a youth-specific engagement process as well as further engagement with families. Engagement with families who speak limited English was recommended by service providers.

Process

During the forums, an overview of the CYMSU project was provided followed by a brief question and answer period. Participants then broke into discussion groups based on the age cohort they self-identified as being most interested in discussing: 0-12, 13-18, and 19-24. For the family and youth forum, a separate discussion group was also held for the youth in attendance.
In discussion groups participants were asked to provide their ideas for change to the CYMHSU system with focus on the areas of access, navigation and transitions. Based on the focus on prevention that emerged in the discussion at the service providers, family members were also asked to provide ideas for change to prevention. Comments in discussion groups were recorded

on flip charts. Then participants were asked to use three sticky dots to identify three high-impact initiatives that they would prioritize for implementation.

In the youth discussion group, participants were asked to imagine their ideal CYMHSU system and were given materials to draw or build it during discussion.

Participants at both forums were also asked to complete comment forms which asked them:

1. What they heard that they liked
2. What they heard that concerned them
3. What questions they still had

What We Heard

Change the vision statement

At the service provider forum, the project's vision statement was presented to frame the discussion questions. However, participants across all three age cohort groups flagged concerns with the wording of the vision statement. Comments included:

- All three groups felt that "to get better" was not strengths-based or trauma-informed. It also does not communicate anything about prevention and is crisis-oriented.
- 19-24 group suggested that the vision statement should delete "to get better" and end with "the services and support they need."
- 0-12 group suggested that "to get better" be replaced with "to improve function", "to thrive," "to improve how they navigate their mental health," or "to achieve mental wellness."
- 13-18 group questioned the use of the term "trauma-informed" as being unclear and difficult to understand.
- 0-12 group felt that the term "mental health" is problematic
- 13-18 group felt that "mental health and substance use" should read "mental health and/or substance use."

Improve the engagement process

Participants in the service provider session had a number suggestions for improving the engagement process for the development of the CYMHSU strategy. Suggestions included:

- Engage families who speak limited or no English
- Going to families and youth in their places where they already have relationships
- Work with youth and peer workers and Elders who already have relationships with youth
- Attend youth forums
- Involving youth in planning and/or delivering the engagement process
- Incorporate engagement work that has already been done in communities, e.g. The ninety-four calls to action of the Truth and Reconciliation Commission report

Ideas for Change

During the forum discussion groups, focus group and interview, participants were asked to provide ideas for change to improve the CYMHSU system. The comments generated are captured in the tables below and are grouped into four areas of focus for the project: access, navigation, transition and prevention. Comments were themed into high level "ideas for change" with supporting comments provided in the columns and organized by source – families and youth or service providers.

Although participants grouped themselves by age cohort for discussion groups, many of the comments and ideas were common across age cohorts. To help illustrate the level of support for an idea for change from each age cohort, each of the comments is followed by an initial that indicates the age cohort/s that were the source of the comment.

Age 0-12 = C (children)

Age 13-18 = T (teen)

Age 19-24 = A (adult)

Youth = Y (youth)

ACCESS

Idea for change:	Families and Youth	Service Providers
Involve parents/guardians as partners in their child's care	• Youth should have choice about whether or not their parents/guardians are involved or informed about their care (Y) • Parents should be able to be involved in the treatment process and engage with support services alongside their children (C, T, A) • Parents of children over 19 are especially frustrated because they are completely excluded from their child's care (A) • Clinicians, especially GPs, need education on privacy and confidentiality so it is applied correctly and consistently. "Get FIPPA right!" (A) • Ask youth if they want their parent to be involved in care – but what if they say no? (T)	• Parents/guardians should be involved in MHSU care for their child (C, T) • "Family involvement is crucial to the support, treatment and recovery of children and youth. When we are told by VCH their services do not see parents or include families in counselling we feel that is a glaring and detrimental omission." (T) • The system needs to view parent involvement as healthy and communicate it that way to youth.(T) • Youth need choice around parental involvement, but clinicians need to have a consistent message to youth about how to involve their parents while still respecting their confidentiality. (T)
Provide more support for parents so they can better support their child	• We need a family model – as a parent, I need support to help my child (T) • Parent support groups are only offered once a month. That's not enough when you're in crisis (T)	• Existing parenting support programs are working well and are inexpensive to run, but there are too few available. The number of support groups available needs to be increased across the city and offered in other languages. (T) • Parents need support in the preteen years and education about what is developmentally normal (C)
Work with and within schools to make them a safe place to connect with care	• Services should be integrated in schools (T, A, Y) • One youth spoke about how his VCH Counsellor has one hour/week at his school so she can only see the student/s most in need or in crisis. All others get "bumped" off the list and must make an appointment at the MH Team. (Y) • Education for students should be part of the curriculum as the amount of MHSU education is uneven between schools (T) • Attendance record at schools should be used to flag students for counselling. (Y) • Teachers need to be educated on why and how to protect the privacy of students accessing MHSU care. A youth told a story of a teacher "outing" him for accessing MH treatment in front of his class, which had serious social consequences, "It ruined my life." (Y)	• VCH needs to work more closely with the schools (C, T) • Prevention and services need to be embedded where families already have relationships, including schools (C, T)

Through outreach provide "place-based" services in locations where families and youth already have relationships and trust		• Relationships are key for getting youth and families to engage in care and for supporting smoother transitions (C, T) • MHSU services should be available through community centres, neighbourhood houses and schools where families already have relationships established. (C, T) • Services need to be decolonized in order to create access for Aboriginal families and those who are marginalized/do not trust the system, i.e. move away from rigid medical model thinking and language, refer to people as "partners" rather than "patients" or "clients," provide service where and when people already spend time in the community. (C) • Some children and youth cannot get into schools because they are new immigrants, new students, or other reasons. Many do not have a GP. Outreach is needed to connect with them (T)
Create one clear access point	• There needs to be one clear access point (T, Y) • Create a telephone hotline to support navigation and educate families about all of the services (T)	• One telephone number to call to access care would facilitate access for families and service providers (T)
Support doctors/primary care clinics to help families access care	• GPs don't know where to send you (A) • GPs need to be more sensitive and have more time to talk with families about MHSU, not just write prescriptions. (A) • Integrate medical care with counselling – there is a need for integrated multidisciplinary care (T)	• Provide Mental Health First Aid training to Medical Office Assistants in Primary Care Clinics and Community Health Centres (A) • Have more Nurse Practitioners available (C) • How do we increase access to GPs for this population? (C)
Make the experience of receiving care more welcoming and positive	• Give youth more choice in their clinician and a greater diversity of clinicians to choose from as their needs change (e.g. gender, personality, approach, etc.). (Y) • Allow for greater choice in where youth receive care (Y) • Mental Health Teams offices need to be more welcoming and supportive (A)	• Consistent relationships are key to connecting youth to services and keeping them engaged (T, A) • Give clinicians the time and resources they need to build relationships, e.g. going for breakfast together (A) • Allow youth choice in their clinician and allow them to change clinicians if it isn't a good fit right at the start. There is a need for greater cultural diversity among the professionals available (T) • Meet youth where they are at and believe them (A) • Allow older youth greater autonomy in deciding their goals of care (A) • Provide financial support for transportation and child-minding (T) • Clients tell us the tone of the VCH staff can be not very youth friendly and can be off-putting (T) • Physical spaces need to be more youth-friendly. They often have plexi-glass, gates and lots of doors. Engage youth in design. (T) • Mixing age groups (and levels of severity) in clinic space can make clinical spaces feel unsafe. (T)

Create better, more accessible communications materials	• The VCH website needs improvement. Needs to be clearer. (T) • Branding is needed (T)	• "Parents are going online for information and resources rather than going to agencies. They feel a lot of shame. But when they go online they don't get the social support" (T) • Youth don't know about services. Create a centralized resource for youth and keep it up to date by crowdsourcing, like Wikipedia (A) • Client information materials should speak to youth, not just adults. (A)
Make help available right away when a family or child/youth needs it.	• "Be there 24 hours a day, when inspiration and/or desperation strikes" (C) • There should be no waits for psych-ed assessments (C)	• Not providing timely support/care/treatment can lead to crisis which results in a need for more intense care/treatment (T) • Providing timely access to addiction services is very important. Children and youth should never have to wait to access services in community (T, A) • Youth often have difficultly waiting for appointments or to undertake long-term treatment (T)
Educate families and professionals around voluntary vs. mandated treatment and secondary care	• Clinicians tell you, "We can't do anything unless it's voluntary by patient." (T) • Clinicians need to understand that being a danger to oneself or others is not a requirement for voluntary admission to hospital (A)	• "Parents are increasingly seizing the idea of forced treatment. Some of the private places will send in an interventionist. The kid goes to treatment and then leaves five days later. Parent has to pay for the whole month." (T) • Clinicians need to know that secondary levels of care/treatment are available and how to ensure timely access (T) • The system does not support mandating treatment, but this often means the family often does not proceed with care, resulting in serious consequences for the child/youth. MCFD needs to be more proactive in mandating treatment (T)
Expand the scope of CYMHSU practice to better serve special populations	• The system should provide Dialectical Behavior Therapy (DBT) (C)	• Dialectical Behavioural Therapy should be provided by the CYMHSU system (A) • Children in care of the Ministry need to be prioritized for screening and intervention. Clinicians need to be educated on how to work with these children and youth (T) • CYMH needs to include somatic disorders in their scope in order to be more holistic (T) • There is a need for clinicians specialized in FASD, ADHD and others. Other clinicians need to be educated on how to work with children and youth with these issues. • There are insufficient services for children with developmental disabilities or cognitive delays. They have specific and ongoing care needs and relationships are especially key for this population. (T) • VCH CYMHSU is not consistently fulfilling its stated scope of practice. Children and youth are referred to the hospital for being out of scope when they can/should be within scope of VCH clinicians. (T)

Increase accessibility for clients and families from different cultures or who speak other languages		• A clinician told a story of a youth who she brought to a MH Team who, although his English proficiency was quite good, the team would not see him without an interpreter. No interpreter was available so they referred him to a private practitioner. The family could not afford to pay so he did not access care and dropped out of school (T) • More professionals need to be trained in cultural competency (C, T) • Services need to be decolonized in order to create access for Aboriginal families and those who are marginalized/do not trust the system, i.e. move away from rigid medical model thinking and language, refer to people as "partners" rather than "patients" or "clients," provide service where and when people already spend time in the community. (C) • VCH previously had multilingual health navigators (Cross Cultural Health Brokers?). This was a very useful program for supporting families who speak limited English or come from different cultures for whom navigation is more challenging. (C) • Aboriginal navigators help connect families to connect to the system.
Expand services to youth using opioids and street drugs	• Lower the age limit for access to suboxone (T) • Treatment for youth using street drugs is crucial because of the harm they do (T)	• There is an increasing number of youth using heroin. This needs focus because of the high potential for harm. Needs intensive intervention and support to get detox initially and then longer term support (T)

NAVIGATION

Idea for change:	Families and Youth	Service Providers
Create dedicated "Navigator" roles to support families to find the services they need	• Create parent-to-parent support roles to help families with navigation (C) • Create peer to peer mental health support positions for youth (A)	• VCH previously had multilingual health navigators (Cross Cultural Health Brokers?). This was a very useful program for supporting families who speak limited English or come from different cultures for whom navigation is even more challenging. (C) • Aboriginal navigators help connect families to connect to the system.
Create resources to help families and service providers know what services are available	• Parents are the ones that help their child connect to care but as a parent who do you initially reach out to? (T) • At first contact with the system families should be fully educated on how the system works and then funnelled to the right service.(T) • Branding and greater clarity of websites is needed (T) • School counsellors should know the system better so they can advise youth on how to access the system (T)	• Train parents to be the navigators (C) • One telephone number to call to access care, like a Central Intake Line, would facilitate access for families and service providers (T) • "Parents are going online for information and resources rather than going to agencies. They feel a lot of shame. But when they go online they don't get the social support" (T) • Youth don't know about services. Create a centralized online resource for youth and keep it up to date by crowdsourcing, like Wikipedia (A) • Client information materials should speak to youth, not just adults. (A)
Provide opportunities for ongoing dialogue between VCH and its partners	• There is a need for ongoing conversation between service providers and families (C)	• There is a need for ongoing dialogue between VCH, partner organizations and other stakeholders (C, T) • Regular communication between VCH and BC Children's MHSU programs is imperative and desired (T)
Support doctors/primary care clinics to help families access care	• GPs don't know where to send you (A)	• GPs are often the first point of contact for families and need to be better educated to help families with navigation (T) • Many families do not have GPs. How do we get GPs for families? Make walk-in clinics provide more follow-up support with navigation (C, T) • Have more Nurse Practitioners available (C)

PREVENTION

Idea for change:	Families and Youth	Service Providers
Work with schools to create awareness of mental health and substance use among	• Education needs to be provided to students from Kindergarten onwards. Teach coping skills. (C) • Educate teachers to assess and support kids early on (C) • Ensure the presence of Public Health in schools to support assessment and	• Provide evidence based prevention programming in schools (C) • Educate teachers to identify early warning signs and know what to do next (C)

students, staff and parents/guardians	awareness (C) • Hold information nights in key grades like Grade 8 so parents are educated on mental health and substance use – signs to look for, resources available, etc. (T) • Programs addressing stigma are key. This needs to be in the school curriculum. (T) • Educate youth about possible consequences of marijuana use (T) • Educate parents to reduce stigma associated with MHSU so that they are more open to allowing their child to receive counselling or medication (T)	
Provide support proactively to avoid crisis and catch children/youth with less severe issues	• System will only help you once you are in crisis. (C) • Kids with less severe issues are not supported by the system, so they slip through the cracks (C) •	• Current system will only provide support reactively, once a child or youth is in crisis. (T) • Parents often wait until things are really bad to get help. Provide parenting education proactively and early (T) • Parents need help with their preteens. Provide education to them so they know what is developmentally normal. Fear-based parenting can make things worse (T)
Increase screening and intervention in early childhood	• There should be better/more comprehensive testing (A)	• We need to do outreach in the preschool years. Children are presenting in kindergarten with significant issues. They are isolated because their parents fear the system or have their own mental health issues (C)
Evaluate prevention		• Create evaluative measures in programs and services to measure prevention (A)

TRANSITIONS

Ideas for change	Families and Youth	Service Providers
Support preschool aged children and families to smooth the transition to school		• We need to do outreach in the preschool years to help children be prepared for school. (C) • Children are presenting in kindergarten with significant issues. They are isolated because their parents fear the system or have their own mental health issues. (C) • Focus school transition supports on children in foster care and children who have moved to Canada from other cultures (C)

Create an electronic medical record that allows client information to be shared across sites	• Often when a child or youth moves between services the history is lost (A) • One electronic record should be used across multiple sites like GP, hospital and detox, to improve continuity of care (T) • The system relies on parents and clients to keep track of their history. Youth should be able to access their records (Y)	• We need to prevent youth and families having to repeatedly retell their story (A)
Build relationships to enable successful transitions		• Relationships are key – "warm hand overs" (A) • Support youth to articulate their desired outcomes (A) • Create a team to support youth through transitions - coordinate with clinicians and youth workers (T)
Better support youth transitioning to adulthood	• Youth at this age need support to integrate into their community, e.g. housing, employment, etc. • One youth spoke about how much he loved his counsellor and was very worried about what would happen once he "aged-out" of the CYMHSU system (Y) • Youth and families need to be informed of when they're too old to Children's Hospital and need to go to adult hospital (T)	
Improve the referral process and communication with referral partners		• Clinicians in schools, hospitals, community agencies and VCH teams need to communicate and collaborate to support clients, especially high-risk clients – safety plans should be communicated across agencies (T) • VCH CYMHSU seems to rush to close files. Could files be kept open longer and youth attached to outreach to support them longer term in order to prevent relapse? If school counsellor is involved, inform them when files are closed so they know that student is no longer accessing care (T) • VCH CYMHSU clinicians do not reciprocate in sharing notes with referral partners. It would be great to be included in case conference or to exchange notes (T) • There is inconsistency among VCH clinicians following up and confirming treatment course (T) • Would like to see standard screening tools (e.g. Stan Kutchner's tools) used across agencies to facilitate communication (T) • MH Teams should use email to communicate brief info with other professionals, esp. school counsellors (T)
Provide opportunities for ongoing dialogue between VCH and its partners	• There is a need for ongoing conversation between service providers and families	• There is a need for ongoing dialogue between VCH, partner organizations and other stakeholders • Create a community of practice to support clinicians across agencies and improve communication (T)

What would stakeholders prioritize for implementation?

Family Session 0-12 Age Cohort

- Be there 24 hours a day when inspiration and desperation strikes
- Kids are falling into gaps between severity – need to support those kids who aren't eligible for funding
- Needs to be an ongoing conversation between service providers and stakeholders
- Continuous assessment of needs
- Education for teachers to assess and support kids early on

Service Provider Session 0-12 Cohort

- More programs in schools- evidence based prevention programs
- Invite families in
- Place-based – go where people feel safe and trust
- Socially inclusive services that don't change with a change in government
- Funding to neighbourhood houses
- Ongoing dialogue with VCH and partners with other stakeholders
- Youth/family navigators – peer support
- 0-5 school age isolation. Kids arrive in kindergarten with complex issues that are unknown to the system

Family Session 13-18 Age Cohort

- Services integrated in schools
- Education about MHSU needs to be expanded in schools
- Make families fully involved and incorporated in care
- Electronic files to keep patient files and integrate this between multiple care points

Service Provider Session 13-18 Age Cohort

- Services and prevention that are place-based – connect to schools, community centres, neighbourhood houses
- Outreach – meet kids on the street, schools, at home
- Give clinicians time to build relationships with clients and families, e.g. budget for lunches and food
- Clinicians specializing in FASD, ADHD and others. Provide education.
- Education for teachers, librarians, community centres re: MHSU and trauma
- Responsiveness is critical
- Coordinate with clinicians, youth workers, etc. Create a team to support

Family Session 19-24 Age Cohort

- Get FIPPA right! There is a lack of knowledge among GPs and clinicians (about privacy legislation and what they are allowed to share with family members).
- Increase understanding that danger to self or others is not a requirement for voluntary admission
- Parents, including parents of children over 19, should be able to be involved in treatment process.
- More welcoming and supportive mental health centres
- Youth age 19-24 need supports for integration into community (housing, employment, etc.)

Service Provider Session 19-24 Cohort

- Relationships are key to connecting youth to services and successful transitions – warm hand overs
- Support youth to articulate their desired outcomes – buy in
- Strengths based approach
- Meet youth where they are at
- Early intervention and free MH care
- Evaluative measures in programs and services to measure prevention
- Youth peers

Family Session – Youth

- One electronic medical record is needed and youth should be able to access their records
- Youth should have more choice in their clinician – more options for male or female psychiatrists, more diversity in personality types
- Should be more medication options (allow youth to participate in research and clinical trials of medication) so that I don't use drugs to self-medicate
- Build mechanism to allow supportive professionals (e.g. teachers) to connect and collaborate in care

Next Steps for Engagement

This report contains feedback gathered during the "Ideas For Change" phase of engagement. Further engagement on ideas for change will be targeted to youth, families who speak languages other than English, as well as with VCH CYMHSU staff and will take place in May and June, 2017. Input gathered through this "Ideas for change" engagement will be considered along with best practices from the literature and VCH service utilization data to generate a short-list of high impact initiatives for implementation.

The second phase of engagement will focus on identifying "Priorities for Change." Over July and August, 2017, the range of stakeholders in the CYMHSU Strategy will have the opportunity to participate in deciding which initiatives from the short-list will be implemented to improve the CYMHSU system.

For more information about the stakeholder engagement process for the CYMHSU Strategy, please contact ce@vch.ca