Take me by the hand

Youth's experiences with mental health services in BC

McCreary
Centre Society

The title for this report, "*Take me by the hand*" is a quote from a young person who took part in this project. It refers to the need for young people experiencing mental health challenges to have someone who can support them in accessing services and navigating the mental health system.

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Take me by the hand

Youth's experiences with mental health services in BC

McCreary Centre Society is a non-government not-for-profit committed to improving the health of BC youth through research, education and community-based projects. Founded in 1977, the Society facilitates a wide range of activities and research to identify and address the health needs of young people in the province.

Project Team

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Key messages from young people

> "[Mental health professionals] should be asking youth what they think they need and valuing that a little."

Based on their own experiences of mental illness and mental health services, young people (aged 15-25) picked out the following as the key messages for anyone seeking to support youth aged 16-18 who are experiencing mental health challenges:

Assisting children and youth to engage in healthy activities and promote positive mental health and coping skills is vital to their mental health in later life and reduces the chances that they will need mental health services.

Young people will often avoid seeking help for their mental health concerns because of stigma and fears about what will happen. This avoidance can be reduced if children, youth, parents, and schools are more educated and informed about mental health and mental health services. This education should be comprehensive and begin at an early age.

Young people cannot contemplate accessing mental health treatment until their basic needs such as food and shelter are met. They need stability in their lives and the services they receive.

A major barrier to accessing mental health care is that youth living outside their family home may lose their accommodation if they enter residential treatment. Many more young people would access services if they knew that they would not be homeless or lose their current residence if they sought treatment.

Young people who do want to access treatment are often denied this opportunity because of long waiting lists or their current situation (e.g., if they have no contact address or phone number). Services need to be more readily available and easier to access for young people who are in need of assistance but not in an acute crisis.

Whether entering youth services for the first time or transitioning to adult services, young people need someone who will advocate for them and will help them to navigate the system.

Young people do not feel heard or engaged in their treatment planning and transitions processes. Youth's voices should be included in all decisions which affect them.

Many youth feel ill-prepared to transition out of youth mental health services and are unaware of any transition plans in place for their care. Transition planning should begin sooner and have either youth services extended or specialist services introduced for young people aged 19-25.

Dear policy maker...

I believe there should be more youth services.

Policy Makers
BC,
Canada
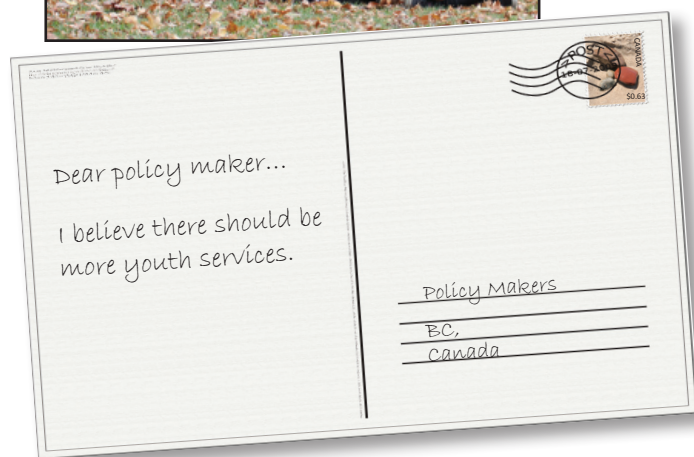
Introduction

In April 2013, the Office of the Representative for Children and Youth released *Still Waiting: First-hand Experiences with Youth Mental Health Services in BC*, a report which looked at the experiences of 853 youth, parents, caregivers, doctors, and other professionals who are supporting youth aged 16-18 who are struggling with mental health challenges in communities across British Columbia.

The report included the perspectives of 89 youth, 70 of whom were recruited for the project by McCreary Centre Society (McCreary). Following the release of *Still Waiting*, McCreary received a number of requests for more details about what youth participants in the project had said regarding their experiences of accessing and transitioning through youth mental health services.

This report summarizes the experiences of the 70 young people aged between 15 and 25 who took part in surveys, and/or focus groups or interviews facilitated by McCreary. The youth had all experienced mental health challenges before the age of 19 and many were still dealing with ongoing mental health concerns.

The report highlights young people's suggestions for how mental health services might be improved, and particularly how planning and transitioning between youth and adult services, and from inpatient services, might be more youth-centered.

Many of the youth's experiences and ideas were echoed by parents and professionals, while others were as unique as the individual young people who took part in this project. The youth's perspectives support the call from BC Representative Mary Ellen Turpel-Lafond for a more "*effective and approachable system*" that can serve young people who are at a critical age in their development and who need the right support and services available to them to assist them in their transition to adulthood.

Methodology

Youth were invited to take part in a two-to two-and-a-half hour focus group and to complete a brief pencil-and-paper survey about their experiences of mental health services in BC between the ages of 16 and 18. Those ages 19 to 25 were asked to reflect back on their experiences when they were between 16 and 18 years old.

Fifteen year olds were also invited to take part in the project, to canvass not only their experiences with mental health services, but also their needs and expectations of accessing services once they turned 16.

Individual meetings were arranged if youth wished to participate in the project but preferred an individual conversation to a focus group. Young people who took part in the project received a $30 gift card. Youth who had not required or accessed mental health services before the age of 19 were not included in the project.

Youth were referred to the project by support workers or informational posters at youth centres. Focus groups and individual conversations were hosted at a range of sites across British Columbia including supported and transitional youth housing, youth centres, housing for homeless youth, mental health resource centres, alternative to custody programs, and residential treatment programs. The sites were located in both urban and rural areas of British Columbia.

Upon completion of data collection and quantitative data analysis for the project, it was found that although participants spoke in person of their experiences living in the North, survey responses did not indicate that youth had lived there between the ages of 16 and 18 years. As a result, an additional focus group was arranged in Prince George so that qualitative information from youth currently living in the North could be included.
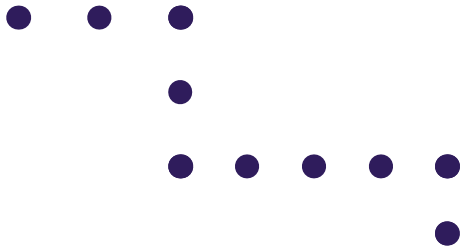
All focus groups and individual conversations followed a similar format. The outline for the focus group was as follows:

Focus group format

I. Introduction to the project

Potential participants were given details about the project, including a request to complete a brief survey and take part in a discussion about their experiences of the mental health system in BC. Youth were told that the information they provided would be included in a project being conducted by the Office of the Representative for Children and Youth to capture the perspectives of youth, service providers, parents, and other caregivers. They were informed that they could stop participating at any point and could decline to answer any questions they did not feel comfortable answering.

II. Community agreement

Participants were given the opportunity to generate guidelines for the discussion. Guidelines included: confidentiality, trust, respect, listening, communication, support, and sensitivity. Participants agreed to these guidelines before the focus group began.

III. Mental health

The first discussion topics introduced to participants were broad and asked youth to describe what mental health meant to them and what factors they felt influenced mental health.

IV. Available community services

Participants then discussed what supports are currently available which are helpful to youth ages 16 to 18 who are experiencing mental health challenges. They were also asked about barriers to accessing these supports, the reasons supports had been helpful and what other services would be useful to youth in this age group.

V. Leaving inpatient care

Most youth who participated in the discussions had experience of inpatient care in BC. These young people were asked about their experience of leaving hospital or other residential services, including transition planning and what supports had been or would have been helpful.

VI. Transitions to adulthood/ adult services

Participants discussed their experiences of transitioning from youth to adult services including their role in the planning process.

VII. Develop a transition map

Young people used creative arts techniques to create a map of the services they have transitioned through, illustrating the process from their perspective, including who had supported them and what was helpful.

VIII. Wrap up

The focus group ended with young people identifying the key messages they wanted to highlight and recapping their main ideas for how the mental health care system could be strengthened to better support 16-18 year olds.
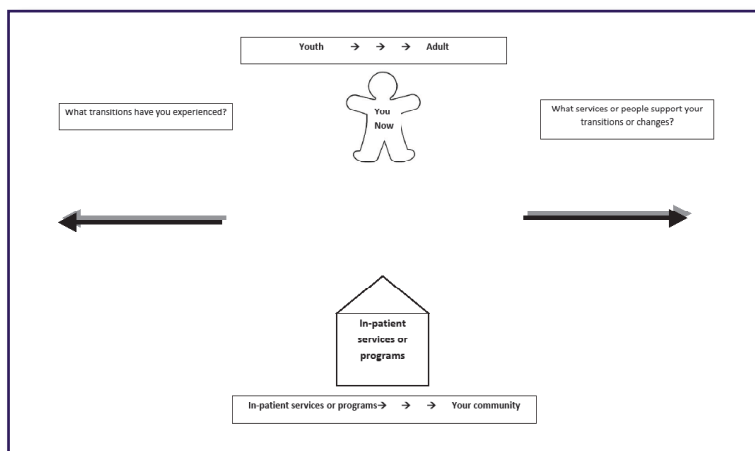
The survey

A brief six-page confidential and anonymous survey was administered to youth prior to the focus group or individual conversation. The survey asked questions about youth's background (e.g., age, ethnicity, home community) as well as specific questions about their mental health diagnoses and their experiences of accessing a variety of services.

The number of youth who completed a survey was too small to conduct many analyses by sub-groups, although these findings are included where possible.

Limitations

It is important to note that this report does not claim to represent the experiences of all youth in BC with mental health challenges or who have accessed mental health services.

The project has captured the experience of young people who were connected to a mental health or other service provider (such as a housing support service). It was not able to capture the experiences of many young people who had successfully navigated the mental health system and were no longer connected to support services. There were also some young people who were experiencing mental health challenges too severe to allow them to participate.

Two participants were interviewed with a support person present (at the youth's request). It is unknown if the presence of this person had any impact on how the youth chose to respond to questions.

Participants in the project acknowledged that as a result of their mental health challenges and other factors in their lives, such as homelessness and substance use, they were not always able to separate their experiences between the ages of 16 and 18 from their experiences prior to or after this period.

Young people we spoke to

In total, 70 young people took part in the qualitative component of the study which was comprised of focus groups (43 youth) and individual interviews (27 youth). Survey responses from 58 youth were included in the quantitative data analyses.

Participants ranged in age from 15 to 25 years, with an average age of 19. Half of the participants were male. Males were, on average, older than females (20 vs. 18 years old). The age range and gender of youth often varied by the site of recruitment. For example, participants from one housing support site were primarily older males (i.e., average age of 22 and 85% were male), while those from one inpatient facility were primarily younger females (i.e., average age of 17 and 75% were female).

Forty-seven percent of youth identified their background as European and 40% were Aboriginal/First Nations (they could select more than one background). Nine percent of youth indicated not knowing what their background was.

Sixty-eight percent of youth identified as heterosexual or straight, 14% were bisexual, and 9% were gay or lesbian.

Between the ages of 16 and 18, 33% of survey respondents indicated having lived in the Vancouver Island Health Authority, 22% in Vancouver Coastal, 16% in Fraser, and 11% in the Interior. Thirteen percent had lived outside BC, and 7% did not specify where they lived during this time period. (As stated earlier, no youth who completed a survey indicated living in the Northern region between the ages of 16 and 18 years, although some youth living in other parts of the province indicated having moved around the province a significant amount, including spending time in the North.)
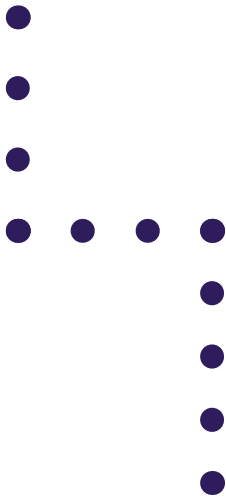
Fifty-six percent of young people indicated that they had lived in their parent's home sometime between the ages of 16 to 18, and 11% had lived only with their parents (and nowhere else). However, youth also lived in a wide variety of other places during this time period. Males were more likely than females to have lived on the street or in a hotel or tent, while females were more likely to have lived in a residential treatment program.

Among youth who completed the survey, they most commonly rated their emotional/mental health as good (40%). While a quarter of males rated their mental health as excellent, none of the females did so.

Lived here at some point between the ages of 16 and 18
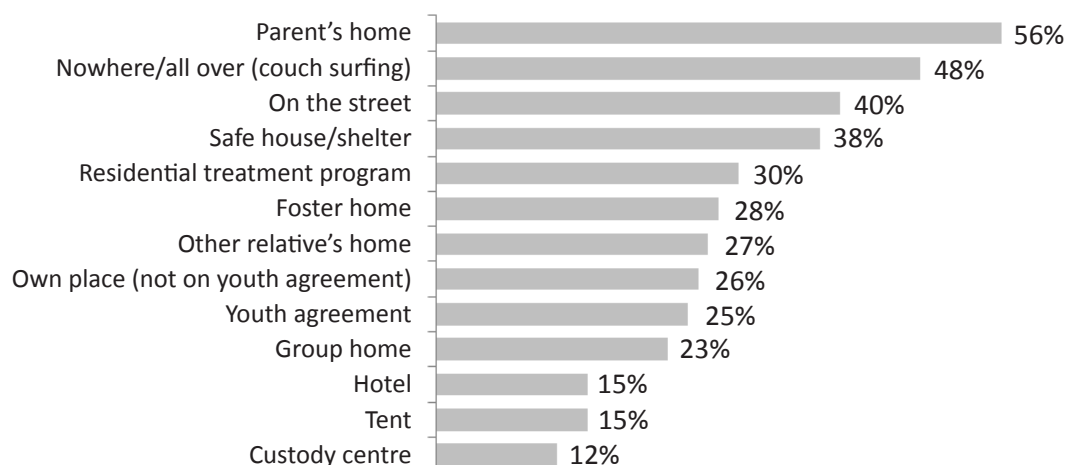
Parent's home	56%
Nowhere/all over (couch surfing)	48%
On the street	40%
Safe house/shelter	38%
Residential treatment program	30%
Foster home	28%
Other relative's home	27%
Own place (not on youth agreement)	26%
Youth agreement	25%
Group home	23%
Hotel	15%
Tent	15%
Custody centre	12%

Note: Youth could indicate more than one response; not all responses are displayed here due to risk of deductive disclosure.

How youth described their mental health between the ages of 16 and 18

Poor	Fair	Good	Excellent
21%	25%	40%	14%
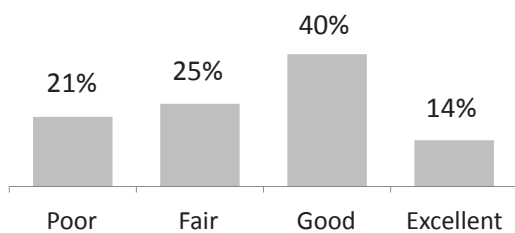
Fifty-nine percent of youth reported having been diagnosed with a mental health problem by a psychiatrist or other mental health professional, and another 16% did not know if they had been diagnosed. There were no regional differences in whether youth had received a mental health diagnosis. However, youth in Vancouver Coastal were more likely than youth in the rest of the regions combined to be aware that they had a diagnosis.

Youth were asked specifically about a number of mental health challenges. For example, more than half (56%) had experienced delusions or hallucinations. Furthermore, a substantial proportion of youth indicated that they "always" had trouble with feeling anxious or stressed (23%); feeling sad, hopeless, or depressed (18%); or with difficulties finishing things they started or following instructions (18%). Females were more likely than males to report having had trouble with binge eating or purging behaviour.

Many youth reported symptoms of both mental health problems and substance use challenges. For example, the majority of youth who indicated often or always having symptoms of depression (68%), psychosis (77%), or problem eating behaviours (88%) also indicated often or always missing important meetings or activities because of their substance use.

Between the ages of 16 and 18, youth who "often" or "always" had trouble with...	
Feeling anxious or stressed	61%
Failing to finish things you start; following instructions	43%
Feeling sad, hopeless, or depressed	39%
Missing important social, work, or recreational activities because of alcohol and/or drug use	33%
Losing their temper	32%
Refusing to follow rules	30%
Experiencing delusions or hallucinations	23%
Destroying others' property; stealing; aggressive behavior	18%
Eating excessively and/or vomiting after eating	14%
Dieting excessively	13%

Fifty-eight percent of young people (43% of males and 74% of females) had experience with inpatient services. For example, many reported that between the ages of 16 and 18, they had stayed at least one night in a substance use treatment program (43%), an Adolescent Psychiatric Unit in a BC hospital (23%), a treatment program for both substance use and mental health problems (21%), BC Children's Hospital mental health services (20%), or an Adult Psychiatric Unit in a BC hospital (18%).

Females were more likely than males to have spent a night in a substance use treatment program (67% vs. 25%). Only a few youth indicated having overnight stays in facilities such as Youth Forensic Psychiatric Services, Maples Adolescent Treatment Centre (Burnaby), Ledger House (Victoria), or in mental health units outside BC.

Youth who had lived in the Vancouver Coastal region between the ages of 16 and 18 were nearly four times more likely than youth in other parts of BC to have stayed overnight at BC Children's Hospital mental health services. There were no other regional differences for accessing inpatient services.

Defining mental health

"[Mental health] is a filter which impacts how you see the world."

"It's what goes on in your head."

Young people were asked to define mental health and what it meant to them. Interestingly, most youth, and especially those who were still experiencing challenges in this area, defined it in terms of mental illness or mental health services, rather than in terms of mental wellness.

"[Mental health is] psychiatrists and counselling."

There were some gender differences in that young women more frequently referred to mental health as being related to traumatic events, such as sexual and physical abuse.

One participant explained that as a result of her experiences, she saw mental health as representing conditions such as bipolar disorder and depression, as well as negative life experiences, including abuse. However, she added that mental health really should reflect how well a person functions and interacts with others on a daily basis.

A group of younger youth (aged 15-18 years) noted that when they thought of mental health they not only thought of it negatively in terms of conditions such as anxiety and depression, but also in terms of something that other people were trying to impose on them. For them the term conjured up memories of *"being told what to do, long meetings,*

> *"I used to think [mental health was] major mental health problems like bipolar, OCD, schizophrenia. Now I think of psych wards and hospitals, and depression."*

anger management programs, taking surveys, and psych wards." Although this was reflective of their experiences, they noted that for people without such experiences mental health would refer to one's well-being, and would include factors such as sleep, appropriate medication, being substance free, having fun and being able to work and participate in community life.

These more positive definitions of mental health were confirmed by youth who were no longer experiencing acute mental health challenges. They talked about mental health in terms of a component of overall health and gave similar examples of reflecting a balanced healthy lifestyle.

One participant suggested that the definition of a mentally healthy youth is someone who is an active part of their community, is able to be themselves, and is able to show people what they are good at.

To define mental health, one group of youth generated a list which read:

- People's state of mind
- "Craziness"
- Alert and wakefulness
- Physical activity and socializing impact it
- Intuition, inner-being, soul

"If you don't want to be somewhere, that affects your mental health."

Barriers to positive mental health

Young people were able to articulate a number of barriers to positive mental health. One group, who had experience of being mandated into one or more residential mental health facilities, saw this attempt to address their mental health issues as having the opposite effect.

It was also noted that by mandating young people into hospital or other residential treatment programs, these youth were removed from their support networks, which compounded rather than alleviated their mental health challenges. Some youth reported that they had been placed in mandatory treatment services and had deliberately sabotaged their care as a result, which had led to more mental health challenges.

A lack of community-based mental health programs was seen as a major barrier to developing positive mental health, particularly for youth living in small towns or rural areas. Without community resources, youth were left in a position where they either had to leave their support networks to get help or had to attempt to manage their symptoms on their own.

Youth in the North spoke of denying that they had mental health challenges because they knew they would have to leave the area to access treatment. They felt that this relocation would exacerbate rather than alleviate any problems they were experiencing, and also felt it was safer to deny their symptoms than have to face the additional risks that they perceived were present in a large city, such as street homelessness and loneliness.
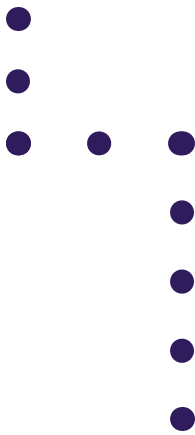
Many young people spoke of using substances to manage their symptoms, and noted being very aware of the negative impact this had on their health and relationships. However, they often felt trapped in a vicious cycle of using substances to deal with problems such as acute anxiety or PTSD which were then intensified as they tried to manage their addictions.

"Mental health is all squished into drugs and alcohol."

The stress of financial, family, or housing problems were highlighted by many youth as reducing the likelihood that they could experience positive mental health, as was the challenge of living with a physical disability or as a young parent.

Living in group homes was seen as another barrier to positive mental health among youth who had been through the government care system. They explained that living away from a family environment and with other youth who were facing challenges compounded their own problems. Living without stable biological or foster family support made it harder for youth to identify what constituted being mentally healthy, especially when the other youth they were living with were also experiencing symptoms of mental illness.

Youth also highlighted that a lack of continuity and consistency in group home rules and guidelines presented a problem for them. They stressed the importance of group home staff being properly trained so that they are sensitive to youth's individual challenges and strengths, and can provide young people with the support they need.

A lack of sleep was also identified as a major barrier to positive mental health among youth who were living in Single Room Occupancy hotels (SROs), shelters, group homes and/or who identified as homeless. Feeling unsafe or fearing that their belongings would be stolen increased youth's anxiety, exacerbated existing symptoms of mental illness, and decreased the amount of sleep they were able to get.

"Being in a good environment and having positive people around you… that's what I needed."

Supports to mental health

Having adequate food, good nutrition, and the opportunity to exercise were all given as examples of elements that helped to make someone mentally healthy. Having goals in life and supports in place to achieve those goals was also considered important.

Supportive relationships were key to many young people. For those without family supports, the support of professionals was seen as vital. For example, one youth felt that social workers had a major influence on young people's mental health, and that the most important role of social workers was to listen to what youth had to say. Others spoke of the importance of youth workers and drug and alcohol counsellors in promoting and supporting their mental health.

Youth identified having a job, and specifically the structure, financial stability, and access to a positive peer group which comes with being employed as helping them to overcome some of their barriers to positive mental health.

A group of Aboriginal youth noted that the biggest positive influences on their mental health were attending counselling and being able to talk with others and feel supported, as well as engaging in sports and activities which took their mind off their problems and provided an outlet for their anxiety and frustration. They also stressed the importance of spirituality in their lives including the association between positive mental health and aspects of Aboriginal culture such as having respectful relationships with elders and Mother Nature.

Suggestions from youth

- Ensure all youth have access to healthy food and a safe place to sleep.
- Provide more social workers, counsellors, and mental health support workers to ensure youth in every community can have access to support when they need it.
- Reduce waiting lists to access community mental health supports (where they exist).
- Increase the number of foster homes available and open these foster home placements up to youth currently living in group homes.
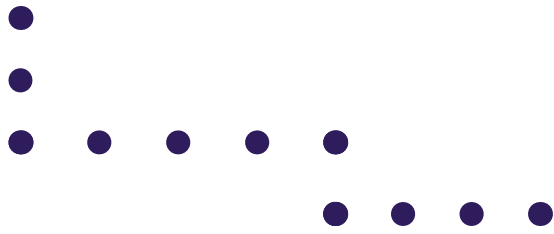
Accessing services

When asked about their experiences with mental health services from the ages of 16 to 18, young people who completed a survey most commonly accessed hospital emergency services (75%), mental health counselling (68%), and alcohol/drug counselling (60%).

Young people aged 19 and over who were reflecting back on their experiences between the ages of 16 and 18 were more likely to recall having accessed a crisis line when they were aged 16-18 than those currently in that age range (31% vs. virtually none). The most common support person (outside of friends and family) whom youth had accessed was also different in that youth currently in the 16-18 age group were most commonly accessing a school counsellor, while those who were 19 and older remembered that youth workers had been their most accessed source of professional support during these years.

Youth who lived in the Vancouver Coastal region between the ages of 16 and 18 were more likely to have accessed detox services during that time compared to youth who lived elsewhere in BC (62% vs. 29%). They were as likely as youth in other areas to have accessed the various other services.

There were some links between youth's living situations and their rates of accessing certain services. For example, youth who experienced precarious housing (lived on the street, in a tent or hotel) between the ages of 16 and 18 were more likely to have accessed mental health counselling or treatment than those who had lived in more stable situations. Similarly, compared to youth without government care experience, rates of accessing mental health counselling or treatment were higher for youth who had stayed in foster care (93% vs. 60%) or been on a Youth Agreement (92% vs. 62%).

Precarious housing linked to accessing mental health counselling/treatment between the ages of 16 and 18
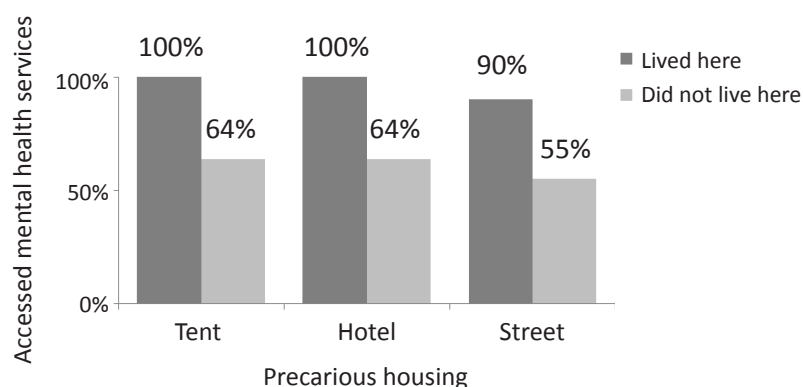
Further, the greater the number of living situations which youth had experienced, the more likely they were to have accessed mental health counselling or treatment.

Fewer than 5% of youth indicated that they wanted to access various mental health services but could not. The only exception was family counselling, where 9% wanted to access this service but were unable to do so.

Youth who reported more frequent symptoms of mental health challenges were more likely to have accessed certain services. For example, 90% of youth who indicated often or always feeling sad, hopeless or depressed reported accessing mental health counselling or treatment, compared to 55% of youth who indicated less frequent symptoms of depression. Youth with more frequent symptoms were also more likely to access combined mental health and substance use treatment.

Furthermore, the more mental health challenges a youth experienced, the more likely they were to have accessed combined mental health and substance use treatment. For example, 59% of youth who regularly experienced at least two categories of mental health challenges (e.g., anxiety and binge eating/ purging) sought combined mental health

"Seeking out help wasn't a step I was ready to make."

More frequent mental health challenges linked to greater likelihood of accessing combined mental health and substance use treatment

Chart: "Accessed combined MH and SU services" (y-axis, 0% to 80%) vs "Mental health challenge" (x-axis).

Legend:
- Often or always experienced the mental health challenge
- Less frequently or never experienced it

- Anxious/stressed: 46%, 14%
- Depressed/hopeless: 50%, 24%
- Illegal/aggressive behaviour: 70%, 26%
- Binge eating/Purging: 75%, 27%
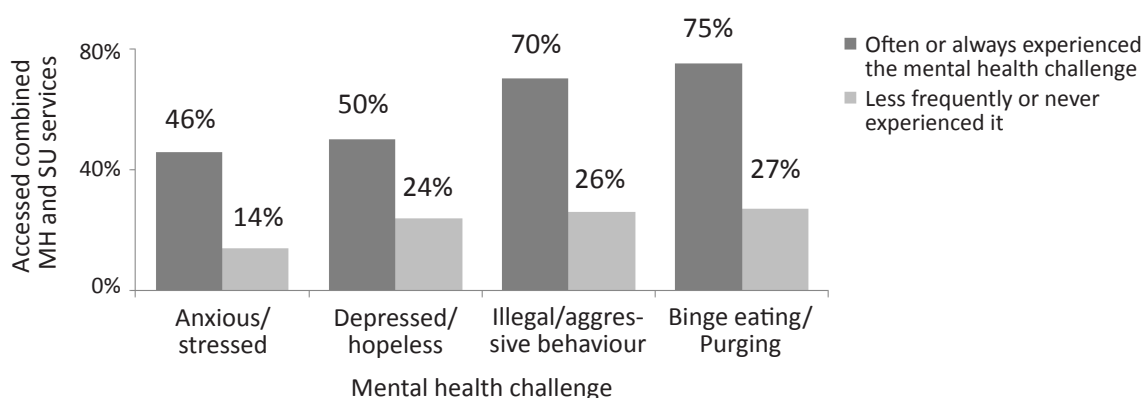
and substance use treatment, compared to 18% who rarely or never experienced these challenges.

In addition to the information they provided on the survey, young people were asked in the focus groups and individual conversations about their experiences of accessing a range of mental health services. They were also asked about services which they had been denied or had chosen not to access between the ages of 16 and 18, and the possible reasons for this.

Many reported that they had chosen not to access any kind of community or hospital mental health service during this period of their life. Although they had

not accessed services at the time, in most regions of the province both rural and urban-based youth felt certain that these services would have been available to them if they had decided it was something they had wanted. They also noted that it was easier to access services in the 16-18 age bracket than it was later in life.

"There are no drop-in services available [for youth aged 19-25]."

"Once you get to my age [23] there's nothing."

However, youth in the Prince George focus group felt certain that the only mental health services available to them locally between the ages of 16 and 18 were those provided as part of services

for concurrent disorders. They believed that to access specific youth mental health services they would have had to leave town, and some youth had chosen to use substances to manage their symptoms rather than leave their home community.

Reflecting back on the transition to adulthood, young people noted that although they may have been resistant to accessing services at the time, support in adolescence is key to ensuring that youth get the help they need as early as possible.

Barriers to accessing services

Although the majority of youth had said that services were available to them if they had chosen to access them, it was clear that certain barriers likely contributed to youth's decisions to not access services.

Forty-three percent of young people surveyed indicated that they had needed emotional or mental health services between the ages of 16 and 18 but did not get them. The most common reasons

Reasons for not accessing mental health services between the ages of 16 and 18 (among those who felt they needed them)
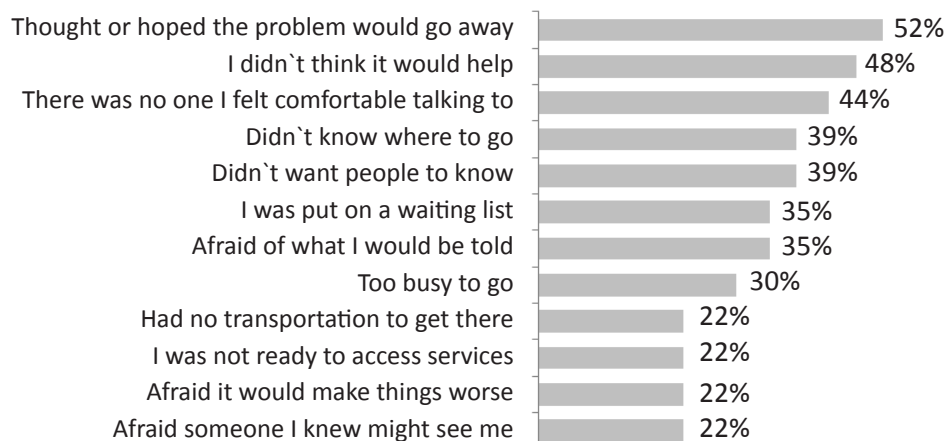
Thought or hoped the problem would go away	52%
I didn`t think it would help	48%
There was no one I felt comfortable talking to	44%
Didn`t know where to go	39%
Didn`t want people to know	39%
I was put on a waiting list	35%
Afraid of what I would be told	35%
Too busy to go	30%
Had no transportation to get there	22%
I was not ready to access services	22%
Afraid it would make things worse	22%
Afraid someone I knew might see me	22%

Note: Youth could indicate more than one response; not all responses are displayed here due to risk of deductive disclosure.

for not getting the help they needed included thinking or hoping the problem would go away, thinking services would not help, feeling there was no one they felt comfortable talking to, not wanting people to know, and not knowing where to go. Nearly a third (30%) of young people who did not access needed services cited all 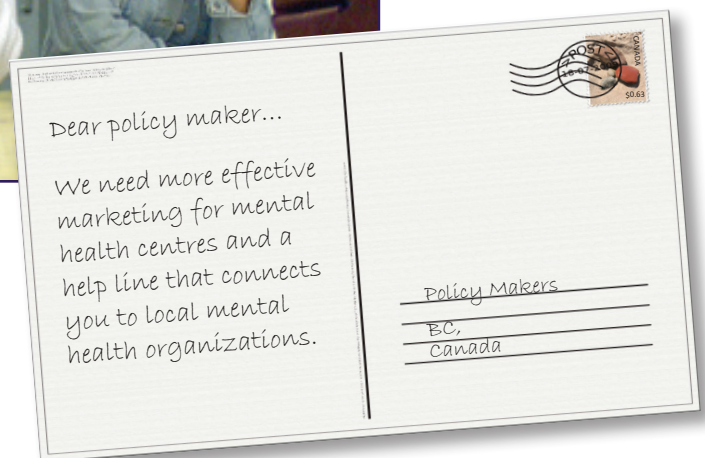three of the most common reasons (i.e., thinking the problem would go away, thinking the service would not help, and feeling there was no one they would feel comfortable talking to).

On the survey, 15% of male and female youth felt they had been denied necessary emotional or mental health services between the ages of 16 and 18. The rate of being denied services was comparable across BC regions. All the females who reported that they were denied services between 16 and 18 years of age were aged 19 and over. They felt that one of the reasons they were denied service was because they were too old at this age (16-18 years) for the service that was available. None of the males reported being denied service because of their age.

In addition to forced choice options on the survey, youth were given the option to add their own reasons. These included feeling that they would not be believed or listened to, being too unstable, and having no psychiatrist available.

Dear policy maker...

We need more effective marketing for mental health centres and a help line that connects you to local mental health organizations.

Policy Makers
BC,
Canada
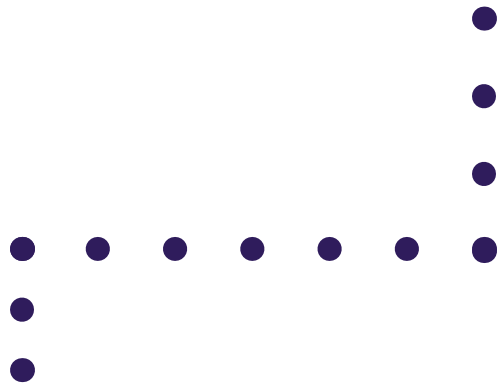
Services did not feel relevant or safe

In the focus groups, one young man summed up what many thought when he suggested that it was "*up to the person themselves*" to be open to accessing services. There could be every possible mental health service available in a community but if a youth was not ready to create changes in their life and was not ready to accept and address their mental health needs, they would not access the service.

Some of the youth who had chosen not to access services reported that between the ages of 16 and 18 they had been reluctant to admit to themselves or others that they were in need of services. These youth preferred to attempt to manage their symptoms in isolation (often using drugs and alcohol to self-medicate). They also reported feeling scared that if they acknowledged they were experiencing problems with their mental health, they would be stigmatized and forced to accept treatment.

"When you start looking you can find a whole other world for help, but if you're in denial you don't seek it out."

This fear of being labeled, stigmatized, and forced into treatment was also common among those young people who had acknowledged that they needed help and had initially sought it out. They felt that psychiatrists and other mental health professionals they had encountered when they first attempted to access treatment were judgmental, and as a result they had made a conscious decision to not pursue accessing any more services.

"People will know and think they're crazy."

Other youth reported that it was their symptoms which prevented them from accessing services. Examples they gave included being withdrawn; agoraphobic; having a fear of change; and feeling anxious, depressed, or hopeless.

Some youth talked about not realizing services were relevant to them, and not recognizing themselves in any of the advertising for services.

"Someone has to take your hand and show you these services, they're not just for the homeless guy in the doorway."

A few young people cited as barriers a lack of assertiveness skills and an inability to advocate for themselves. They reported that they had made attempts to discuss their mental health concerns with their primary health care providers or other professionals but had been dismissed and their issues minimized.

Youth living in small towns and who were from rural and remote communities noted that a lack of alternative peer groups (and therefore different perspectives) could lead them to avoid services if their friends had had negative experiences or pressured them not to access services. Another youth in an urban setting echoed the potential negative role of peer groups even when they were attempting to be supportive:

"[Friends] are not qualified professionals and are still perceiving the world as children, so they sometimes give bad advice."

Believing that they needed parental/guardian consent to access some services was a barrier for youth. Related barriers included a fear that their parents would find out about their problems; that youth's confidentiality in their diagnosis and treatment would be breached; and that youth would lose control of their own information. This was of particular concern to youth who had been suicidal or who had been sexually abused. Youth also knew that they could not access private mental health services such as counsellors or psychologists without their parents' involvement because of the prohibitive cost.

> *"You need to be able to get away from the situation that brought you here in the first place."*

Poverty and unstable home life

Youth who had grown up living in poverty noted that they had been unable to access extracurricular activities and opportunities to make healthy connections with others in their community when they were growing up. This had not only influenced their mental health by leading to feelings of social isolation, but had also meant that when they began to experience mental health challenges they had not considered mental health services to be something they could access.

The low amount of welfare benefits available to youth living with mental health challenges was considered to be a barrier to both their mental health and their access to services. Youth mentioned being unable to return to school, eat properly, or focus on getting well when they had so little money to live off each month. They also suggested that the process of transitioning from a Youth Agreement to welfare or disability benefits was not clear. Their confusion and frustration led them to disengage from services which compounded the problems of living in poverty.

Homelessness was repeatedly mentioned as a barrier to accessing services. Youth had to put meeting their basic needs, including food and shelter, above accessing services, making and keeping appointments, and filling prescriptions. Moreover,

they noted that even if they were staying in an SRO or other temporary accommodation, they would lose their place if they went into hospital or another mental health facility and would be street homeless when discharged.

Youth who were precariously housed or living in SROs also expressed that it was challenging to go from residential treatment back to their SRO if they had to return to the same situation they had left. Therefore, they felt there was sometimes no point in seeking treatment.

"You don't want to go back to what you had before cause that's what brought you down."

Suggestions from youth

- Ensure all youth have a safe place to stay and do not lose their home if they have to enter a residential facility. (Having a stable home allows youth to return to school or find a job and this in turn improves mental health.)
- Offer low barrier services which provide food and shelter as well as mental health support.
- Provide affordable and accessible recreation programs, such as activities at community centres, which are interesting and engaging for youth.

> *"Mental health is a huge thing and it should be addressed more with young people."*

Lack of clear information

Youth reported that mental health is not addressed in most high schools, and the services that do exist do not reach out to youth who are struggling. Instead, youth are expected to seek out help on their own.

"High school - there's nothing on mental health."

One youth said, "Y*our average kid doesn't know what's going on*" in terms of the availability of mental health support and care. Others suggested bringing mental health information into Planning classes in high schools:

"There's no mental health information given at school. It would be helpful to have nurses or psychiatrists or any health care professional give information sessions, talk about services and mental health conditions and dispel myths."

"Mental health should be addressed while you're still developing, and education is key to removing the stigma associated with mental health."

A lack of information about what to expect when youth access mental health services prevented many young people from accessing any services between the ages of 16 and 18. For example, they thought they would have to pay and could not afford to do so, or they were afraid they may be forced into hospital against their will.

Youth who had attempted to access services reported that they often got confusing and contradictory messages which made it hard to navigate the system and often led to them withdrawing from services. They were often unsure of the different roles of professionals they encountered, and as a result were unsure about whose advice they should follow.

"One person will tell you one thing and another something else."

Young people reported feeling that their ability to access services was too reliant on the knowledge-base of individual workers. This was of particular concern to youth in care who did not have an adult in their family who could advocate for them.

"I need an advocate."

Without the help of knowledgeable and supportive professionals, youth were unclear about what they needed to do to get an appointment for mental health services and how to access these. If their particular school counsellor or social worker did not know how to refer them or navigate the system, the youth felt powerless to do this as they did not have any information about locally available services.

Youth also suggested that more relevant and available information on mental health would make it easier for family and friends to recognize signs of mental health challenges and problems. They felt that this could help with preventing mental health challenges from escalating and help provide support for youth experiencing challenges. This suggestion seems particularly timely given that 96% of youth aged 16-18 who completed a survey were seeking the support of their friends (above professionals and family). This percentage was higher than the 72% of older youth who had asked their friends for help at this age.

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Suggestions from youth

- Assign one worker to each youth who will help them navigate through the system, including from community to hospital and back to the community if needed, as well as from youth services to adult ones.

- Advertise the mental health supports that are available in each community because one of the biggest barriers is a lack of knowledge about what services are out there.

- Have school counsellors promote their services more, and advertise that they can maintain a level of confidentiality in the services they provide.

- Provide youth in school with more information about what to expect if they access mental health services.

"I'm tired of asking for help, because I don't get help or don't get a response."

Waiting lists

Long waiting lists to access mental health professionals or treatment facilities were considered to be a major barrier for youth wherever they were living. In Vancouver, this was a bigger problem for those living in SROs around the Downtown Eastside than in some other parts of the city. Some noted that they had phoned mental health services or applied for them in person, but had never received a follow-up call or response to their application. Others noted that when they were street homeless, they had often been without a cell phone or contact number so even if services had responded to their requests for help, they would have been unable to reach the youth.

Some youth spoke of being on waiting lists of 12 months or more. One felt she remained on a waiting list for services for over a year because younger children were given priority when it came to diagnosing mental health challenges.

Youth who had felt well served by hospital-based programs, such as Vancouver Coastal Health's Early Psychosis Intervention Program, said that although acute inpatient services had been readily available, the waiting list for a community psychiatrist had been a barrier to accessing services after discharge from hospital.

Suggestions from youth

- Ensure more psychiatrists are trained and available to work with youth.

- Ensure that there is continuity of care between services when youth are transferred from one health care service to another, or if they move communities.

One youth reported that initially she had a very positive experience accessing services. She was referred by her general practitioner (GP) to a psychiatrist and seen immediately. However, that psychiatrist moved away from her community and she was left without mental health support for over six months when she was not stable. When she was finally offered support again, she was then "*bounced around a lot*" among various mental health professionals, and was unable to build therapeutic or helpful relationships with these service providers.

Lack of accessible youth mental health services

Youth from small communities noted a lack of services altogether. They spoke about how their families had had to advocate for them and about having to travel to urban centers to get the care they required. Youth from the North noted that there was a lack of mental health services available across the region as well as in their specific community.

 "There's nothing available here [for mental health]. There's foster homes and that's it."

A lack of youth-specific care in some small towns in BC meant that youth either entered a local psychiatric unit with adults or they had to travel to the youth psychiatric ward in a larger city such as Kelowna or Vancouver, where they were isolated from friends and family.

"[It is] annoying when you have to go from one place to another to get services."

One youth reported that he had moved from one small town in the Interior to another four years ago, but still had to return to the first town to access mental health care as nothing was available where he currently lived. Another rural-based youth noted that there was "*not very much that was convenient*" in terms of mental health services.

Youth in Vancouver noted it was much easier to access drug and alcohol services than mental health services because there were more of these services readily available. They also perceived that whilst using drugs and alcohol might be a barrier to accessing mental health services, the reverse was not the case; in their experience, having a mental health problem was not a barrier to accessing substance use services.

Participants also pointed out that mental health and other support services that mixed youth and adults did not create a supportive or youth-friendly space, and was not something they wanted to access.

"Look around some services, and it's people over 50."

Having to keep weekly appointments was too restrictive for some young people, as was the lack of a central location for services because young people had to travel around to access different types of support.

Other issues of access included services not being accessible by public transportation, a lack of alternative transportation, services not being open when youth could attend, and age restrictions on services.

Dear policy maker...

Teaming up counselling with youth groups, and proactive involvement in community could be really helpful.

Policy Makers

BC,
Canada
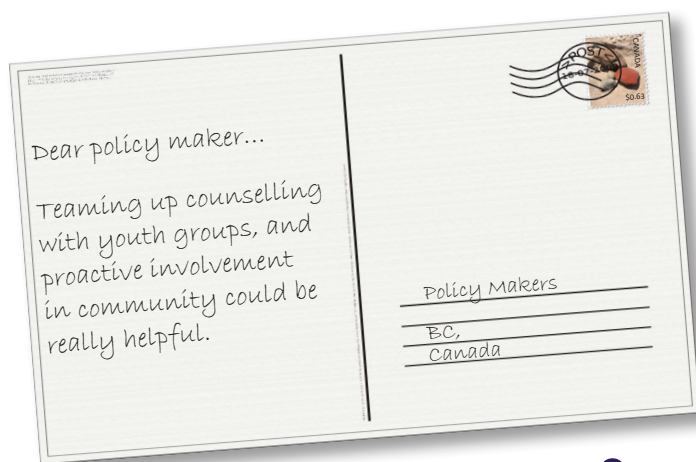
Suggestions from youth

- Mental health supports should be separate from adult services and be available at facilities that youth already access, such as youth drop-in centres and youth homeless shelters. This would make the services physically and emotionally easier to access because they would be available at a place where youth felt comfortable and safe.

- Create a "one stop shop" where youth can access social workers, social assistance, disability, and mental health support. This would make it easier for youth to navigate all the systems and government ministries that are involved when youth have a debilitating mental health condition.

- Offer more local community-based treatment programs. This would allow youth to re-establish or maintain their family ties while continuing to receive treatment and care.

- Identify youth's transportation issues and provide appropriate assistance for them to attend appointments. This could range from offering help with the cost of transit, meeting them at a convenient location, or picking them up and dropping them off for appointments. Youth in the North also suggested coordinating services' opening hours with local public transit hours of operation.

"It's like we don't have a voice."

Discrimination

The majority of participants felt that professionals did not take young people seriously or respect their views. They felt that mental health professionals often made decisions without considering youth's wishes and perspectives when treating them and making decisions about their care. One youth felt that mental health professionals took her more seriously when she turned 19, but even then did not help her access the supports that she felt she needed.

Youth found that the welfare system was discriminatory against young people with mental health conditions and was unsupportive of those who were attempting to access disability benefits and social assistance. They felt that the forms and processes they had to go through to access social assistance were often too complicated for them to understand and were not clearly laid out in terms of what they were entitled to.

"The system's messed up… they don't tell you what's going on."

Youth who identified as lesbian or gay reported experiencing discrimination within mental health services which made them feel unwelcome. Youth who were learning English also reported experiencing discrimination because a lack of multilingual services meant that they were effectively denied service.

"There's no women's services unless you're pregnant."

Young people who were parents talked about the additional stress that having a child can put on their mental health, and how services do not often cater to youth with children. For example, child care is not provided for youth to enter inpatient mental health treatment and even accessing community services can be overwhelming for a parent of a small child.

Suggestions from youth

- Young women who would not access mixed gender facilities felt that more female-specific treatment programs were needed. They explained that female-specific programs helped them to feel more comfortable and enabled them to relate better to the other participants. (However, it should be noted that both males and females who were attending gender-segregated programs suggested that there should also be more co-ed programs.)

- Provide more Aboriginal-specific supports and services.

- Provide multilingual resources and services that are more culturally aware and sensitive.

- Ensure mental health professionals are open to discussing young people's concerns about the services they are receiving, in an open and non-defensive way. They should also acknowledge if they have made a mistake in relation to the young person's care or have acted in a discriminatory way.

- Provide child care and parenting classes to support youth who have their own children.

> *"I'm not going back there again when I feel people don't listen or understand."*

Individual relationships

Young people who had accessed mental health supports between the ages of 16 and 18 reflected back that they had felt frustrated with not having had enough individual time with their assigned support workers and treatment teams. They felt that professionals did not take the time to get to know them and therefore did not really understand their mental health challenges. Youth had often not fully explained their symptoms and issues because they had never felt comfortable confiding in professionals whom they rarely saw.

The quality of the therapeutic relationship was also a source of frustration which led young people to disengage from services. For example, one participant recalled being assigned a youth worker because of her mental health challenges. Despite seeing this worker on a weekly basis, they never discussed or addressed her mental health issues, and there was no one else assigned to

address these issues. Another youth talked about ceasing to access services because he felt staff had no personal understanding of mental health challenges and could not relate to him as a result.

Another youth who disengaged from youth mental health services because they *"just treated all patients the same"* felt that doctors asked questions and provided medication, but did not take the time to get to know youth and understand their experiences. He likened the mental health services he had received to *"fishing with a net when they should be using an individual hook,"* as each youth was unique and required individualized care. Another reported that she attended an outpatient program for youth ages 10 to 18 when she was 17 years old. She did not feel she fit in because she was older than the other participants.

Dear policy maker...

[We need] more
workers with more time.

Policy Makers

BC,
Canada

Suggestions from youth

- Ensure support staff have some lived experience of mental health and other challenges – "*someone who knows how to deal with stuff and who knows what they're talking about.*"

- Allow youth to switch counsellors or psychiatrists when they cannot relate to the person assigned to them.

- When young people are accessing mental health services, have peer mentors available who understand what it was like to live with mental health challenges.

  "People who have been there, done that."

- The "*flexibility of the system needs to be increased as everyone's situation is so unique.*"

> *"Sometimes the substance use was caused by the mental illness."*

Substance use

Youth reported that if they had an underlying mental health problem as well as a substance use problem, they were more likely to be treated for their substance use than their mental health problem. This left them feeling that they were only linked into half of the services that they needed.

Suggestions from youth

- Integrate mental health services into drug and alcohol services as they are often connected. One youth suggested that she could only fully address her substance use if she could also receive assistance to address her mental health issues.

  "I can't fix my head because it needs to be medically treated."
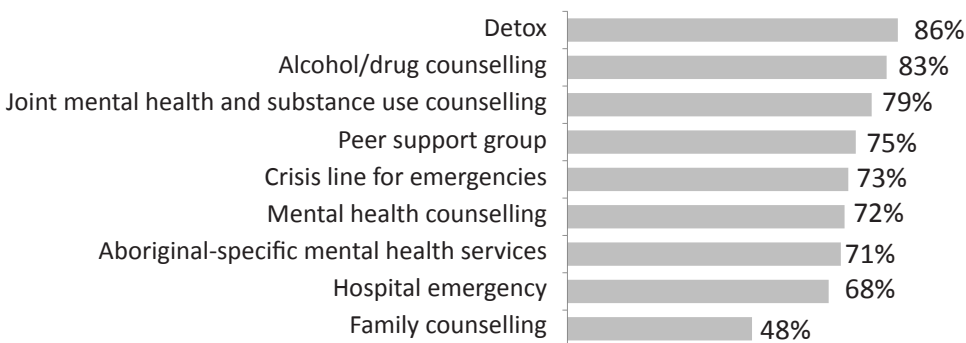
Supportive Services in BC

Youth who accessed services indicated on the survey that they had generally found them helpful. This was true for all youth regardless of gender, ethnicity, sexual orientation, or age. One regional difference was that youth who lived in Vancouver Coastal between the ages of 16 and 18 were less likely than those in other BC regions to have found family counselling helpful (0% of youth in Vancouver Coastal found it helpful vs. 64% of youth in other BC regions, among those who accessed it).

Youth who took part in focus groups and interviews discussed the benefits of having ongoing support from the same mental health professional over the years. They explained that having a consistent, long-term relationship with a professional allowed them to develop a trusting relationship, which they felt was key to their successful treatment. They said that once they trusted the professional, they felt safe confiding in this person and accepting support from them.

There was generally no link between youth finding the services helpful and their mental health status between the ages of 16 and 18. However, youth who had found their relatives or nurses to be helpful sources of support were more likely to rate their mental health as good or excellent on the survey, compared to those who found the support to be unhelpful.

Mental health services that youth found helpful (among those who accessed help)

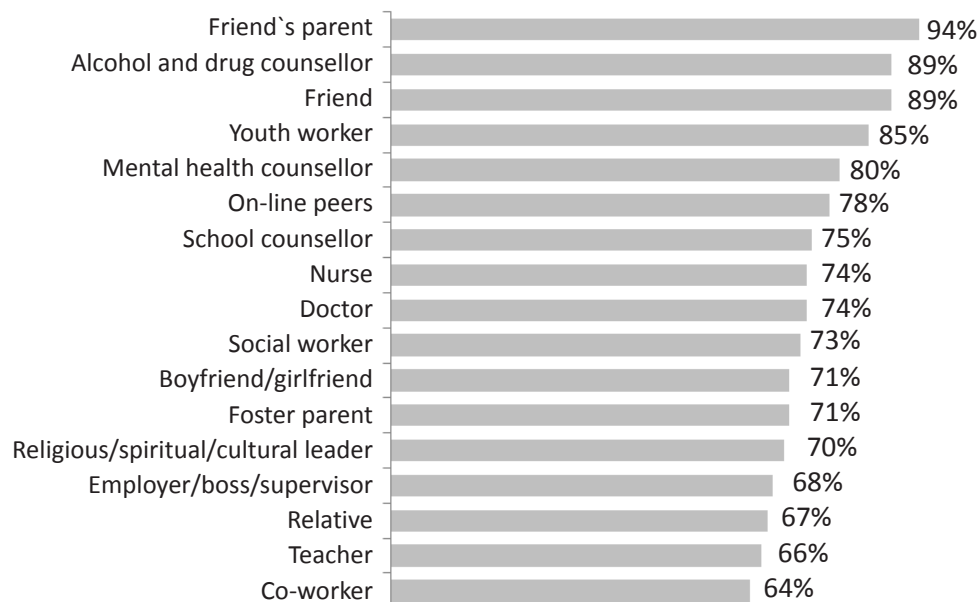| Service	Percentage
Detox	86%
Alcohol/drug counselling	83%
Joint mental health and substance use counselling	79%
Peer support group	75%
Crisis line for emergencies	73%
Mental health counselling	72%
Aboriginal-specific mental health services	71%
Hospital emergency	68%
Family counselling	48%

Note: Youth could indicate more than one response; not all responses are displayed here due to risk of deductive disclosure.

Reflecting on their support networks between the ages of 16 and 18, participants had asked a number of people for help, including a relative (84%), friend (81%), school counsellor (73%), boy/girlfriend (72%), youth worker (71%), teacher (68%), mental health counsellor (64%), nurse (64%), doctor (63%), social worker (62%), friend's parent (61%), and alcohol and drug counsellor (63%). Each young person surveyed had asked at least one person for help between the ages of 16 and 18. Among those youth who

had asked for help, at least six out of ten found these sources of support to be helpful. Females were more likely than males to report that mental health counsellors and alcohol and drug counsellors were helpful sources of support.

Among youth who sought help, Aboriginal youth were more likely than non-Aboriginal youth to deem as helpful the support they received from relatives (89% vs. 53%) and teachers (87% vs. 50%)

People whom youth found helpful (among those who asked for help)

Friend`s parent	94%
Alcohol and drug counsellor	89%
Friend	89%
Youth worker	85%
Mental health counsellor	80%
On-line peers	78%
School counsellor	75%
Nurse	74%
Doctor	74%
Social worker	73%
Boyfriend/girlfriend	71%
Foster parent	71%
Religious/spiritual/cultural leader	70%
Employer/boss/supervisor	68%
Relative	67%
Teacher	66%
Co-worker	64%

"Everything I want I can get."
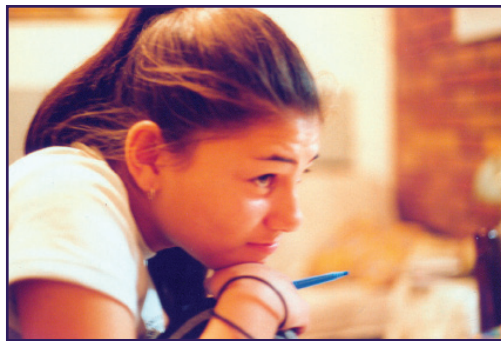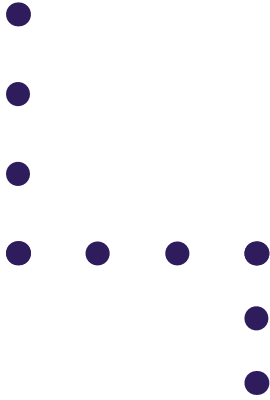
Specific mental health services

In the focus groups and conversations, youth singled out services offered through Coast Mental Health in Vancouver and Burnaby as being supportive. Although some youth who had accessed these services were unable to provide concrete examples of what was helpful, others noted that it was because they felt cared about. They were particularly grateful for follow-up support and regular check-in's after they left the hospital, for example, from the Inner City Mental Health team and at Covenant House. They believed this follow-up support not only demonstrated that the professionals cared about them, but also provided continuity within their mental health care.

"It's cool how they stick with you."

The Early Psychosis Intervention program was highlighted as a successful program and it was suggested that this same approach be used to support youth with other mental health conditions. Its success was attributed to being free of charge, community-based, comprehensive, and providing a holistic package of care through skilled and caring workers who work in partnership with the youth.

Youth from North Vancouver Island praised the Delaware program run by John Howard Society of North Island as a successful youth-friendly mental health support service. Delaware offers a place where youth can come together and prepare food, access free meals, meet new people, and talk with workers. It is a youth-friendly space that is based upon the needs and ideas of youth. The youth particularly praised the group meetings and the flexibility of the program workers who would pick them up if they needed a ride and were very willing to reschedule meetings to accommodate the youth's needs and schedule.

Although youth in Prince George were not aware of any youth-specific mental health services, they praised Intersect Youth and Family Services, the Native Healing Centre, and the Future Cents employment program for the mental health support offered at these places. Additionally, the life and employment skills they acquired through programs like Future Cents had a positive effect on their mental health even though improving youth's mental health is not a specific aim of the program.

A young woman suggested that going to a women-only treatment facility changed her life, and noted "*It made me who I am today*." It was there that she "*started to have my own voice and stand up for myself*."

Services that extended past their 19th birthday provided youth with continuity and ensured that supportive, meaningful relationships were not lost. In one community youth were able to access their drug and alcohol counsellors until they turned 21, which they felt was important to their mental health. They thought that the consistency and continuous support was very helpful, especially in a small town with a shortage of services.

One young woman who had been in a substance use residential treatment program far from her home community had found this experience helpful. Particularly useful were the routine and structure, learning basic life skills (such as how to do laundry and cook), interacting with peers who had similar experiences, and getting a break from stressors which existed within her home community.

Telephone support lines were also noted as helpful and frequently accessed, particularly by youth in small and rural communities who had no in-person alternatives or who were worried about confidentiality.

Other support services

Participants valued youth centres and youth programs, such as art programs, which had helped them develop skills, access informal supports, and find their passion. As a result, these programs helped them to feel happier and to reduce or stop drug use. Boys and Girls Clubs and job placement programs were identified as particularly helpful in offering informal support for youth with mental health challenges.

Youth aged 19 and older who were reflecting back on their experiences noted that helpful, supportive teachers and other school staff had played a large role in promoting their positive mental health and assisting them in times of crisis when they were aged 16-18.

Youth noted that the structure which was present in a range of services was beneficial to their mental health, even if it was not a specific mental health facility. For example, a youth housing program in the Interior region was praised for offering structure and routine to homeless youth who had previously lacked this in their lives.

"[Covenant House] gives me a space to open up."

Youth in Vancouver singled out resources for homeless youth such as Directions and Covenant House as providing a supportive, listening, and caring environment which helped promote their mental health.

One young man suggested that the harm reduction framework of the building he lived in was very helpful for him. He felt that "*people need the supports to keep them safe*" and that people in the building he lived in knew and understood each other because they were all struggling with similar issues.

> *"I love younger staff. I do connect with them, but there needs to be boundaries."*

Supportive relationships

"She listens, and then when you make a suggestion she gets right on it."

One-on-one support and adult monitoring was seen as key to supporting youth with mental health concerns. The presence of someone who was trustworthy, consistent, reliable, and accessible was critical.

When asked about helpful support services, youth had difficulty listing such services but could more easily name and identify helpful individuals, such as specific youth workers, drug and alcohol counsellors, therapists, psychiatrists, psychologists, and Intensive Support and Supervision Program (ISSP) workers. Several youth noted how grateful they were to ISSP workers in particular for driving them to services and appointments. One said, "*We just get a coffee and drive around and talk. She's really easy to talk to, she's nice. A lot of workers tell you what to do, but she listens.*"

Having a supportive Probation Officer was considered to be important by youth in conflict with the law. One youth said, "*Even though she pisses me off, it's good to know she's there for me.*"

Another noted the success she had experienced in terms of addressing her mental health concerns, thanks to having a dedicated support worker who had assisted her to navigate her way through the system and who had been available to talk with her, act as an advocate, and answer questions when she did not understand what was happening.

"If there was no one there to take me [to treatment services] I probably never would have gone."

Although some youth had negative experiences of the government care system, others reported that supportive foster parents had helped them work through challenges in their lives, and advocated for them to get the mental health care they needed. For some youth, being on a Youth Agreement had eased their mental health challenges because their basic needs were dealt with.

"Youth Agreements depends on the person if they are good or bad. It really helps that they help pay the rent."

Young people identified mental health professionals who had been particularly helpful to them. These were people who:

- Treated them with respect
- Remembered them and what was going on in their life
- Gave them positive feedback
- Asked questions and included them in decisions
- Did not stereotype
- Did not judge them for their substance use, but sought to understand the underlying mental health challenges that led to the substance use
- Helped them set and meet goals
- Offered some structure in their lives
- Included them in their diagnosis rather than just giving them a label
- Explained their diagnosis to them and what services and supports they could access
- Were flexible and creative
- Completed the tasks that they said they would (e.g., made referrals)
- Took the time to build and engage in an ongoing relationship with youth
- Kept professional boundaries
- Acted as a positive role model
- Were knowledgeable about local resources and how to access them
- "*Did not treat me like a number*"
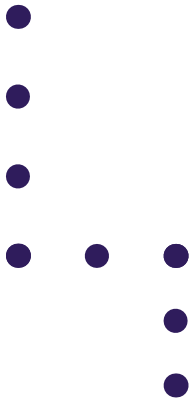
Family and friends

Family and friends may be sources of support for young people, particularily when they feel their health professionals' support is inadequate. One youth felt his medications had not been monitored correctly and that he had been given little education about his condition from the mental health professionals in his life. However, he remarked that he did receive emotional support from family and friends which he felt had replaced the support that the professionals should have been providing.

Others noted that family and friends could play a particularly vital role when youth themselves were not able to recognize they were ill.

For some youth who had been through the government care system, reconnecting with their birth family was seen as important for mental health. For others, finding a supportive foster family was more important. All agreed that whether their family was biological, adoptive, or a foster family, their support was essential because these adults could act as advocates in helping to ensure that they received adequate care.

Access to appropriate medication

Participants felt it was important to ensure that youth who needed medication were medicated correctly. They explained that once youth were stabilized on their medication, they were able to more fully participate in decisions that affected them.

Youth also felt that once their medication was stable, they could then address issues in therapy, which was not possible when, for example, they were having intrusive thoughts.

Employment

Young men in particular noted that working at a paid job was an important part of their lives and helped them with their mental health and addiction challenges. They felt that work was helpful because it kept them occupied and focused, helped them set realistic goals, offered structure, and gave them money to live on. However, they also noted the difficulties that can arise in finding a job once youth have lost one because of mental health challenges, and of the need to educate employers about mental illness.

"[Working] keeps you occupied, helps you set realistic goals 'cause you know where you have to be at a certain time… You start making money so you can actually live your life."

For young women, employment was important because it provided a regular routine, income, and balance; but they also highlighted that stable housing, positive work relationships, and the ability to maintain connections with their support workers were equally important.
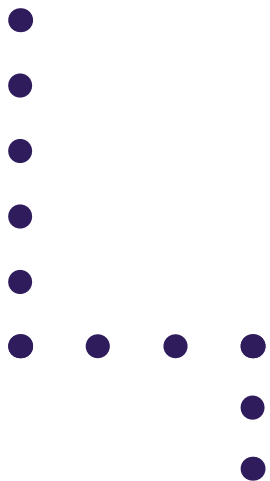
Additional supports and services that youth would find helpful

More prevention and early intervention

- More wellness centres are needed where the focus is on healthy living and overcoming mental health challenges. Wellness centres would allow youth to spend time in a supported environment, as well as participate in workshops on wellness.

- Having more inpatient facilities and qualified mental health workers would increase the likelihood of earlier intervention. Children and youth who are experiencing problems could then be correctly diagnosed and supported sooner, and with the least disruption in their lives.

- Offer education and support in school about abuse and sexual exploitation so that youth know how to access help or avoid situations which might later impact their mental health.

- More prevention services are needed, including training front-line workers such as teachers, police officers, social workers, and bus drivers around mental health. This could help prevent challenges escalating into situations of crisis.

- The media should showcase more positive stories around mental health.

- As youth are most likely to talk to their peers about their problems, there should be more accessible information for young people around mental health challenges and available services. This would enable young people to identify when their friends are experiencing problems.

More resources

- There are not enough mental health workers to work with children and youth, so more need to be trained. There is also a need for more school counsellors, advisors, and mental health specialists within the school system (including elementary schools) who can offer support, education, and awareness about mental health. This would not only help to inform young people struggling with mental health challenges but would also educate their peers and reduce stigma.

  "There is no [mental illness] preventative education and awareness building but if your son was on drugs or was suicidal, then you can get supports."

- It would be helpful to have pamphlets in school counsellors' offices, with explanations of mental health challenges and a list of available supports in the community. Posters that scare young people about mental illness act as a deterrent to seeking services.

 *"Posters like 'psychosis sucks' are not helpful because they don't explain what psychosis is."*

- Educating parents is important so they are better able to identify and understand their children's mental health challenges.

- Social workers and other professionals should be trained to hear and understand young people's perspectives and to work alongside them in a respectful way. They should also have the time and resources to leave their office and meet youth in a place that feels safe for the young person.

Reducing stigma

- A number of youth based in Vancouver suggested that services needed to be located in different areas of the city rather than being concentrated in a downtown neighbourhood that can feel unsafe.

  "Put a youth shelter on the good side of town, in a nice neighborhood, maybe on the west side [of Vancouver]."

- Youth from outside Vancouver suggested that providing services in a youth's community/town would help reduce the stigma. They said that people notice a youth's absence if they have to leave town to get treatment, which is a deterrent to seeking treatment and makes the transition out of inpatient care more challenging.
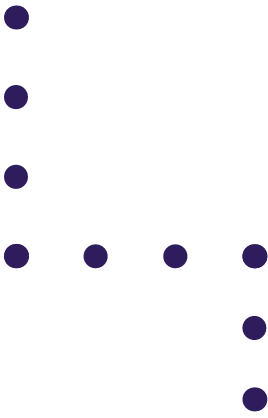
"Someone almost needs to take your hand."

Improve impatient experiences

- There should be a clear and understandable complaints procedure in every residential treatment program which ensures that youth can file complaints, have their complaints taken seriously, and experience no negative repercussions.

- Doctors in the emergency room (ER) and mental health practitioners should have a good 'bedside manner' so that youth feel respected and heard.

- Just as peer mentors would be useful when accessing community services, having someone work with youth who is close in age and has gone through similar experiences would be helpful to young people who need to access inpatient services.

Individualized care

- There should be individualized care and supports to reflect the unique needs and goals of each youth.

- Youth services should be divided by age because older and younger youth have different needs due to their different developmental stages.

- More programming should be provided that is fun, engaging, and comprehensive. For example, include an occupational therapist, life-skills training, and relaxation techniques rather than just focusing on mental illness management.

Leaving inpatient care

A group of young people who were currently receiving inpatient treatment and were aged 16-18 had many ideas about what the transition back to community life would be like. They believed that they would be well supported in their transition and that this support would continue beyond their 19th birthday.

"You can still receive mental health services when you're older."

They expected to continue to attend treatment groups, to receive support from social workers and after-care support workers, as well as from family and friends. Some spoke of expecting to be assigned a housing support worker who would assist them to find housing and work with their social worker to get them on a Youth Agreement. (The ability to go on a Youth Agreement seemed to be very important to youth who wished to move away from home situations which they blamed for their mental health challenges.)

"I would want to be able to continue treatment or groups."

Another group of youth who were also currently in a substance use residential treatment program seemed unsure of what would be available to them when they left. While they looked forward to

things like having a job, making new friends, and developing a better relationship with their family, they appeared to have little idea about who might support them with these goals.

Most youth who had experienced the transition from inpatient care, either into another treatment option or back into the community, were unable to recall any transition planning taking place or were adamant that none had occurred. One youth who was in a psychiatric ward of a hospital for almost six months felt there was plenty of time to involve him in transition planning but he *"wasn't asked about what [he] wanted at all."*

"[Transition planning], I really don't think it's there."

"There was no transitioning process."

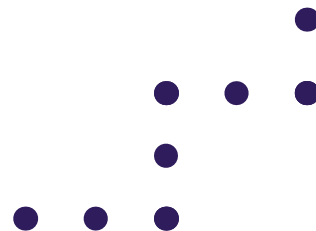> ## "I felt pressured. I had no choice or options. I had to go there."

Despite not recalling any transition planning, around 25% of the young people who participated in focus groups or interviews felt they had transitioned successfully back into community life.

Young people who had been through St. Paul's Hospital in Vancouver noted that transition planning did occur. For some youth this was very helpful but others felt that their after care options were so limited that the planning process was pointless.

Similarly, youth who returned to rural areas after a stay in hospital or other residential treatment program noted that no transition planning had occurred because there were no services or follow up care available in their community.

While most young people could not recall any transition planning, all agreed it would have been helpful. Many were able to remember feeling they had been discharged early and/or without any exit plan and that this had been a very negative and harmful experience. Some even believed they had been excluded from transition planning because the inpatient facility was afraid that they would run away if they knew what plan was in place for them post discharge.

Dear policy maker...

I would create a free art/creativity studio where young local talent come together and create, and put on workshops/free concerts—encouraging people to get creative and stay clean.

Policy Makers
BC,
Canada

Supporting the transition from inpatient care

Although the majority of youth could not speak to any type of transition planning taking place, planning by the Early Psychosis Intervention program was praised. One youth reported that his care team started talking about transitioning about 3-5 months before he was due to be discharged. He reflected that having this much notice and planning time was helpful, and made him feel cared about and that the team was "*really wanting to help their clients*."

Youth who had active biological or foster families talked about the important role they played in ensuring a successful transition out of residential services. Their family members would act as an important support and attend their appointments with them. They would also act as an advocate to ensure that the youth got the care they needed, were not discharged before they were ready, and that community supports were in place.

For example, one youth spoke about how his foster family had advocated for a transition plan to be put in place before he left hospital so that they could prepare beforehand. This had made the youth feel safe and supported by the foster family, and had led to a smooth and successful transition back into community life.

Another youth talked about how his transition plan had not been a formal one but that it included everyone with an important role in his life such as his ISSP worker, Probation Officer, his community-based counsellors, his family, and his true friends.
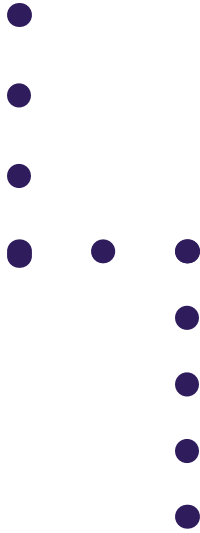
Returning to their home community or moving to a new community

When clear communication occurred between the hospital and community support, the transition was eased for youth. Examples of this working well were given in Vancouver and North Vancouver Island.

"St. Paul's, they got me in here and sent them my background info first which was cool because then they knew what happened at St. Paul's… It shows effort."

"When there are people here [community services on North Vancouver Island] waiting for your social worker's thumbs-up, it helps that they can call each other."

Youth who were currently receiving inpatient care felt that one of the biggest challenges with going home would be returning to the same situation that they were in before they left. They felt that something would need to change in their home life but were unsure how to make this happen and how this could be supported. In fact, rather than think of how they could be supported, they suggested that youth should have the opportunity to go on Youth Agreements so that they could have their own place to live and go out on their own.

"When you get out of treatment you feel like an alien."

One youth in the Interior spoke of how their transition from residential psychiatric care to a supported group home and eventually onto independent youth housing had been successful because it was a slow and planned process. This youth praised the way the residential treatment centre had given them day passes in combination with support from workers, which allowed them to gradually move back into their community and to have access to subsidized youth housing.

> *"Luckily I developed other supports, like friends and family. I think I was more the exception than the rule."*

Available supports for young people after leaving inpatient care

Young people currently in any form of residential treatment were hopeful that their support workers and psychiatrists would still be in contact with them and "check up" on them after they transitioned out of their current location. However, youth who had been through the process were much more likely to say that nobody had been available to support them after leaving inpatient care. One youth gave an example of being released from hospital with no ride home and no access to transit. As a result, they walked home and felt abandoned.

"Once you're out of the hospital you're just completely left."

Another youth felt that he was initially involved in pre-discharge conversations about what services he wanted to access when he left the youth mental health program; however, the actual transition came abruptly and in reality he was not given a choice around which services he was transitioning into. As a result he lost a helpful and supportive relationship with a social worker and he was transferred to someone he did not develop a good relationship with.

"You work with a person, then they're not your person anymore."

Youth who could speak to having continued support mentioned staying connected with psychiatrists, mental health teams, day programs, and support groups. However, this was not always positive, as one young woman spoke of being forced to continue to travel to see her inpatient psychiatrist every time there was a problem with her medication or she needed a prescription or other assistance because no one in her local community was considered qualified to offer her care. This made it challenging to establish support networks in her community.

Youth who had been able to connect to support groups when they returned to their community spoke of this easing the transition and allowing them to receive education and support while working closely with health care workers.

Suggestions from youth to improve the experience of leaving inpatient care:

- Inpatient treatment should be no longer than six months in duration to ensure youth do not become institutionalized or lose connections within their home community.

- Transition planning should begin as soon as youth enter treatment. Without such a plan youth can feel abandoned, especially if they have lost their home or community supports as a result of going into hospital.

- Even if youth only access the ER for mental health treatment or are in hospital only a few days, there should still be a person assigned at the hospital to help them transition back into the community and ensure they have a place to stay, access to medication, and follow-up appointments. This person should take responsibility for contacting the youth and checking in with them. They should not wait for the youth to get in touch.

- Have services that can accommodate different issues. This centralization would prevent youth from having to move to one facility to access treatment for their substance use and then to another for treatment of their eating disorder, forexample.

- Develop similar transition planning processes to those of the BC custody centres which include liaising with foster placements and community services.

- Also learning from custody centres, young people in inpatient mental health facilities should have the opportunity to get adequate exercise and time outside. A lack of exercise and constantly being indoors can negatively affect mental and physical health and make the transition back to community life harder.

"We need more knowledge, less waiting time, more workers in rural towns."

- Just as a peer mentor would be helpful in initially connecting youth to services, such a person could also develop a relationship with youth while they were an inpatient and assist them to acclimatize to life back in the community.

"Adults have their own opinion on what is best, but they didn't move out at 16. It's rough. They don't know the reality of it. Being a youth now is different."

- Provide the opportunity to have on-going therapeutic relationships with other support workers and mental health professionals.

"[Youth] aren't going to want to share their deepest, darkest secret with someone they haven't known that long."

"It is pure will, wanting to do it."

- Having a transition plan which included ongoing counselling, ideally with the same counsellor, was identified as important so that young people could continue working through the issues they had been dealing with while in hospital.

  "Don't start from ground zero."

- There should be communication and file transfers among the relevant practitioners to facilitate a smooth transition for the youth from one service to another.

- Young people should be moved up community wait lists for services if they have no other supports in their life.

- Parents and family should be more engaged in transition planning and should receive more information from health care providers. Several youth noted that their parents were unsure of how to support them, how to access services, and how to order and refill their prescriptions when they left hospital.

- After being in residential treatment, youth should be able to go into a transition house where they could still receive mental health care on an outpatient basis and gradually build up links to services and supports in the community.

- Young people who are going to be discharged to live alone should be taught how to deal with spending time on their own, which they do not experience in a residential setting. Any transition preparation should include teaching youth stress management skills, and the tools to deal with living in a less structured setting.

- Planning for discharge should include more training in basic life-skills, including money management, medication management, and cooking, because having these skills alleviates some of the stress of trying to reintegrate into the community.

- Unplanned and sudden discharges from inpatient treatment with no follow-up care or support should be avoided.

- Finally, some youth felt that a successful transition needs to come from inside them, rather than from anything a program or professional could offer. However, they did acknowledge the importance of having mental health professionals assist them in reaching their goals.
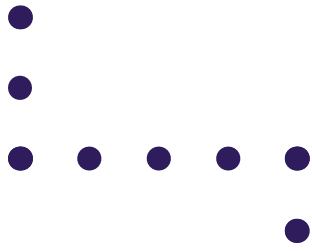
Transitions to adulthood and adult services

Younger youth appeared to be excited at the prospect of transitioning to adulthood. Many of them expressed hope for the future in terms of moving into employment and developing stability and meaningful relationships in their lives. However, they appeared to have no knowledge of how this transition might occur and what support would be available to them if they needed it.

"I don't know about my choices."

As youth neared the transition to adulthood, they appeared less enthusiastic about it. Some of the youth who were aged 17 and 18 appeared particularly unsure of the services they would be able to access as an adult, and found this uncertainty stressful. They felt that no one had prepared them for transitioning into adulthood and they did not know what to expect.

Transitioning out of youth services and into adult services or away from services altogether was traumatic for the young people who had experienced this. Youth spoke of not only losing services but losing important adult allies and significant relationships with social workers and youth workers. Being taken off a Youth Agreement and losing the attached funding was also very difficult and overwhelming.

"When I was 19 they basically told me to 'have a nice life'."

While most youth found the transition out of youth services difficult, one participant thought it was a positive event and *"helps you grow up."* He likened the transition between youth and adult mental health services to the transition between elementary and junior high school.

"It's hard to go from system to system."

"It felt like I was asked to build the wall of China, without giving me the tools, without telling me the specific steps to take."

Another youth who had positive experiences of the transition to adult services felt that while youth services were chaotic and crisis-focused, adult services were more open to providing long-term care. However, she did note that her transition from youth to adult services coincided with a move from Vancouver to a smaller city where there were shorter waiting lists to access psychiatrists and other service providers.

Participants who were in their early 20's who reported that they were successfully transitioning to adulthood, despite not having a transition plan or support services in place to facilitate this transition, all noted that they were living in stable homes and were employed.

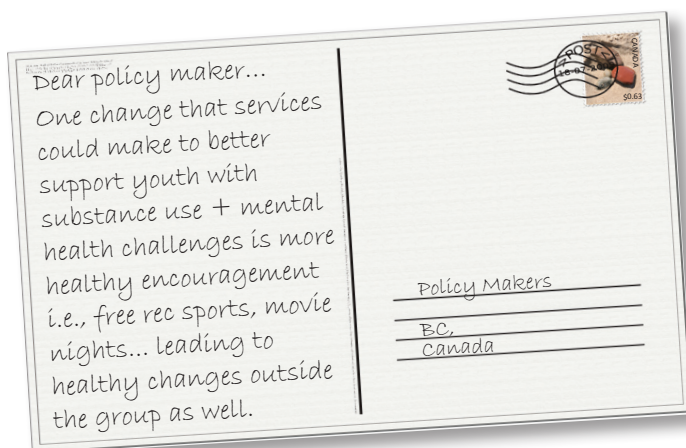## Helpful supports for young people as they prepare to age out of youth services

One youth highlighted the helpful role that a housing support worker had in preparing them for the transition out of youth services, and suggested that all youth ageing out of youth services needed an advocate who would help them to plan for their future. Others spoke of caring and supportive social workers.

Vancouver-based homelessness services such as Covenant House were noted to be particularly helpful to young people transitioning into adulthood as they assisted youth to find housing

and offered some stability. This in turn helped youth to manage their mental health issues independently when they were no longer being supported by the youth mental health system. However, youth were aware that homelessness services should not be where youth are conditioned to go for mental health support. One said that relying on shelters and other homelessness services for support leads to the potential for some other negative experiences and "*a pretty shitty life*."

A group of youth on Vancouver Island reported that their school had been helpful in connecting them with adult services during their senior high school year.

Another youth had a therapist talk to her about transitioning to adult mental health services at age 17. She said it was reassuring that this conversation happened at this age, rather than later on, and that she was given information about which therapists were available to her on a long-term basis and which were not. However, she was left to contact a psychiatrist and other mental health supports in the adult system on her own. She found this very overwhelming and did not feel well enough to deal with the responsibility. Subsequently, she did not contact services for herself and there was no contact or transferring of files between her youth and adult mental health services.

Dear policy maker...
One change that services could make to better support youth with substance use + mental health challenges is more healthy encouragement i.e., free rec sports, movie nights... leading to healthy changes outside the group as well.

Policy Makers
B.C.,
Canada

> **"[I was] left at the edge of a cliff with nowhere to go."**

Planning the transition to adult services

"It's like you're supported and then all of a sudden [the services] are gone, and you're like 'what do I do now?'"

Similar to their experience of leaving inpatient mental health care, most youth we spoke to were unable to talk about transition planning in regards to moving from youth to adult services and supports. They were not aware of any planning taking place on their behalf and were adamant they had not been included in any planning process. Most youth reported simply being discharged from a service when they turned 19 (or earlier) without a transition plan in place.

"When somebody reaches a certain age they get cut off."

"Young people are pushed aside because they are young, they have no experience, and what do they know?"

Also similar to the experience of leaving inpatient care, those who knew of any transition plan being made for their move to adult services felt that they were excluded; or on the rare occasions when they were included, they felt it was tokenistic and their opinions were not valued or listened to. One youth said that a psychiatric report was written about her as she transitioned out of youth services but she did not have any input into it and she disagreed with the conclusions of the report, but had nobody to discuss it with. She felt that this complicated her transition to adult services. During this time, she had to wait many months for community mental health care, and her health deteriorated until she needed acute inpatient care.

"I was left hanging and it was really detrimental to my mental health."

Other youth reported being discharged from their youth psychiatrist and being left with no support for an extended

period of time. They said that this absence meant that not only did they lose continuity of care, but they also had no one to help with medication prescriptions except through walk-in clinic GPs who did not know them or their needs.

Many youth were overwhelmed by the transition process and did not understand most of what was happening (including what the protocols were to access different services and how to complete application forms). Other youth spoke of making a conscious decision to not access adult services or giving up after starting the process because they did not have the energy to keep pressing for services, and found the whole process demoralizing and confusing.
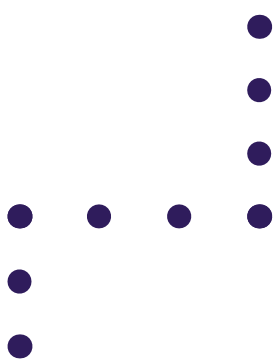
"Things change and there is a lot of complicated stuff."

"Steps need to be clearer because there's nobody really to talk to, you have to figure it out yourself the hard way."

Suggestions from youth to improve the transition to adulthood and adult services:

"Psychiatry and psychology should be accessible to everyone. After 19 is when you need it most."

- There needs to be more flexibility in services to ensure they do not end abruptly when a young person turns 19, either by extending current youth services or by providing specialized services for young people aged 19-25. These should include a specialized provincial inpatient mental health facility, and social workers and counsellors who specialize in working with older youth and young adults.

- Each youth going through the mental health system should have one worker assigned to them who could help them navigate the system. During the transition to adult services, young people need assistance to figure out where to go for a specific service, how to get an appointment, and how to fill out application forms such as for counselling, benefits, housing, and employment.

> *"There should be a transition period from 18 to 25 with services to help you figure out what to do."*

- A support worker should be someone who not only knows the mental health and associated systems and services, but also knows which services would be the most appropriate for the particular young person. This worker would be able to assist youth in accessing a variety of services, including during an out-of-hours crisis situation. The youth should also have some choice in who their transition advocate is, and an option to change the worker if, for example, there was a "personality clash."

- Consider each individual's situation (e.g., if they are homeless, whether they want to stay that way or not) and tailor a transition package from youth to adult services based on each individual's needs rather than on what services might be available, even if they are not a good fit.

- Ensure adult service providers receive a comprehensive hand-over of a young person's information prior to seeing a youth for the first time. This way, the service provider would be aware of the youth's situation and history beforehand. As a result, youth might open up more easily and would not have to constantly re-tell their stories.

- Ensure youth know where to go to access adult mental health services and where these services are physically located. Also provide more widespread advertising across communities, provide adult services in accessible locations, and offer assistance with transportation (e.g., bus tickets).

- Youth transitioning out of youth services should be taught how to identify triggers and risk factors in their lives as well as positive coping techniques to prevent the likelihood of needing services later in life.
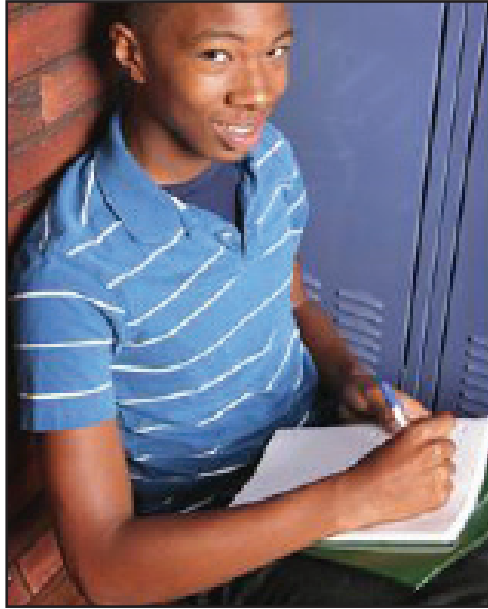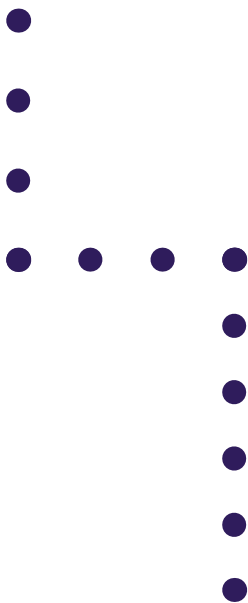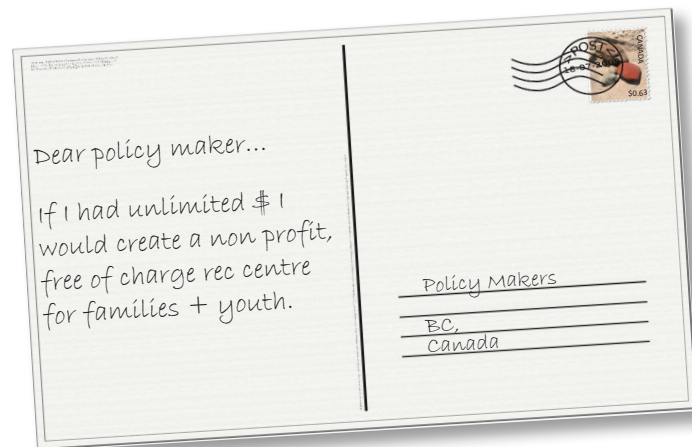
- Ensure privacy and confidentiality with all services so that youth do not feel judged before they walk in the door of adult services.

- Reduce the gap in treatment time during the transition from youth to adult services. During the time without support, young people's conditions may worsen and they may come to need acute care.

  "Sometimes young people can't wait that long."

- Have professionals spend more time discussing future plans with young people as they transition out of services. Ensure these plans are specific and can be broken down into manageable and achievable steps.

- Have youth services follow-up with the young person as they get established in the adult system. For example, monthly follow-ups/check-ins for a year would be helpful.

- Have a more gradual transition process and explain each step fully to young people so that they can better understand what is going on and get slowly introduced to the new services that they will be using.

- Offer peer support groups. Young people who are members of a closed support group should be able to continue to attend after they turn 19. They have already established relationships within the group which would support them to transition through services together.

While youth had many suggestions for how to ease the transition from youth mental health services to adult services, they also repeated that there should be more prevention work done to reduce the number of young people having to go through the system in the first place. For example, they felt that if children and younger adolescents could be given the opportunity to get involved in activities they enjoy doing (such as art activities or Aboriginal-specific activities like beading and making dream-catchers), they could develop a sense of competence. This sense of competence can ease the transition to adulthood, and youth can teach others what they feel they excel at, which could instill a sense of self-worth and accomplishment.

There should also be more accessible programs for at-risk young people which do not require them to "*have committed a crime or to have a formal diagnosis to attend*." This would reduce the likelihood of at-risk youth experiencing more serious mental health and substance use problems later on, and would increase their likelihood of getting the help they need and experiencing a smoother transition to adulthood.

Dear policy maker...

If I had unlimited $ I would create a non profit, free of charge rec centre for families + youth.

Policy Makers

BC,
Canada

Transitions maps

During the focus groups, youth were asked to create a map showing the services and supports they had previously accessed, where they saw themselves now, and what (if any) services and supports they felt they would need to succeed in the future.

Past

Participants' maps highlighted negative previous experiences such as unstable housing, homelessness, addictions, and placement in youth custody. Key supports which had helped youth on their journey through the mental health system were also shown, including youth workers and drug and alcohol counsellors. Older youth generally noted that services were more available and better funded when they were younger, which was reflected in their maps.

Present

In the middle of the map, youth illustrated where they saw themselves currently. Participants who were currently involved in a residential program emphasized the structure and sense of belonging and safety that the placement provided. Youth involved with a range of services also highlighted access to food, peer support, and support from staff at the various services they were utilizing.

Future

Looking towards the future, young people generally saw themselves gaining employment skills, graduating from school, increasing their independence, improving their family relationships, engaging in sports, and taking part in other healthy community-based activities.

In terms of services and supports, they commonly included needing assistance to secure and maintain a safe place to live, a Youth Agreement, and access to mental health services.
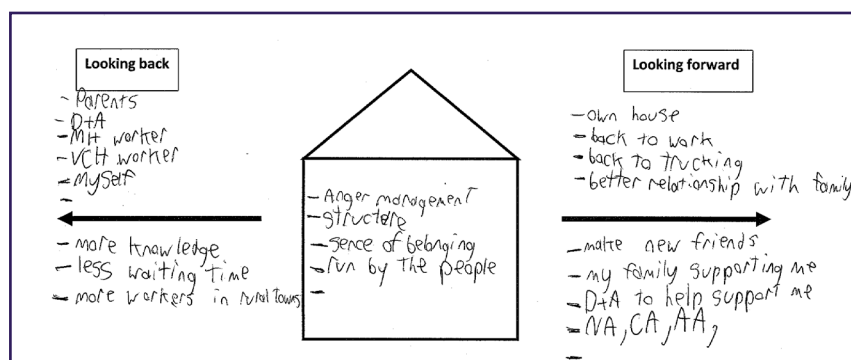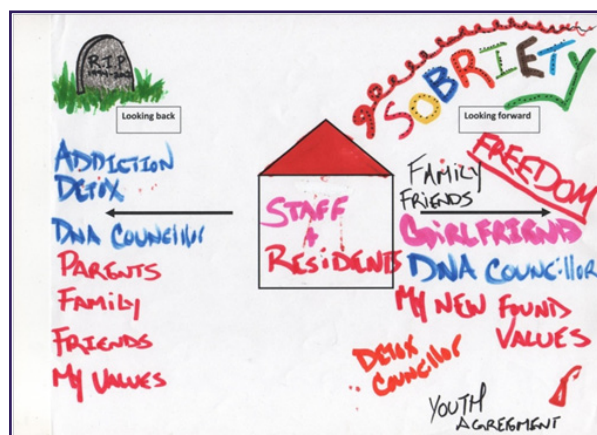
Summary

"*Accept young people where they're at.*"

One youth articulately summed up the message from all youth participants when she said: "*Young people don't think they're being listened to. And if they have mental health issues they feel alone and different, not the same as the rest of the world. They feel their opinions are not up to par.*"

Youth had a number of suggestions for how to prevent young people coming into contact with the mental health system in the first place, and spoke of the need to address issues of poverty and inequality. They also thought that early intervention in their own mental health care may have prevented their untreated mental health issues from escalating to a place where they required inpatient care or developed a substance use problem in attempting to manage their symptoms on their own.

Many of the youth we spoke to had not sought help for their mental health conditions between the ages of 16 and 18, or had made a conscious decision to disengage from services. They took personal responsibility for this. Yet they were able to give many examples where services had not met their needs, they had been denied help or support, or they had been unable to identify where to turn when they needed help. They were also able to clearly articulate what would have made their experiences more positive and what would have helped them seek the support and care they needed.

Young people's suggestions to improve mental health care and transitions through services ranged from systemic changes such as providing services specifically for 19-25 year olds and providing more services in small communities,

to much smaller and quickly achievable changes such as bringing in mental health professionals as speakers to Planning classes in high school.

Whether talking about initially accessing services, seeking emergency care, or transitioning from one service to another, youth consistently spoke of the need to have a navigator who could help ensure they got the care and support they needed. A peer mentor who had successfully transitioned out of the youth mental health system and who was trained to assist youth to meet their mental health and associated needs was considered the most ideal person to fulfill this role.

Youth were also quick to praise individuals and services that had helped them on their journey through the mental health system. They were particularly

appreciative when they received individualized care and supports which reflected their unique situation and goals.

Finally, young people were grateful for the opportunity to have their opinions heard and were keen to be part of a project which they believed might make things easier for children and youth who experience mental health challenges.