

Commission de la santé mentale du Canada

A Foundation for Online Knowledge Mobilization in Child and Youth Mental Health

SYNTHESIS REPORT

February 2014

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RESEARCH TEAMS

Research Projects

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Literature Review & Environmental Scan

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EXECUTIVE SUMMARY

This synthesis report captures the complexities behind what the average child or youth in Canada wants to know about mental health and more specifically, how they search for this information online. This synthesis report is built upon three separate studies: (1) a literature review by Shalini Lal; (2) a qualitative report by mindyourmind; (3) and a mixed methods report by Cathexis Consulting that were funded by the Mental Health Commission of Canada. This report provides a thoughtful discussion about how youth think about mental health. It also provides an opportunity for dialogue concerning how children and youth engage with mental health knowledge online, specifically as evolving technology opens up more possibilities on how we know what we know. Summarized below are six main areas discussed: (1) mental health content; (2) language; (3) stigma; (4) credible sites and information; (5) supportive spaces, places and people; and (6) the online environment.

1 Mental Health Content

Youth do think about and search for information on mental health. Results from the different studies highlight the need to provide mental health content that includes three primary domains of information: (1) positive mental health or mental wellness, (2) mental illness (e.g., myths, symptoms), and (3) help-seeking. Research also indicates that older youth (ages 16 to 18) look for mental health information more than younger youth (ages 12 to 15). Youth use mental health information based on a needs-driven approach. They search for information when there is a reason to do so. Therefore, mental health content should be created in a way that meets those needs.

2 Language

In relation to mental health, research found that there was debate regarding which terms should be used to talk about mental health. Language used to talk about mental health is often geared to adults and not meant for a youth audience, their developmental stage or learning style. That said, youth indicated that mental health content needs to: balance the use of plain language and technical or medical terms; describe distinct concepts and ideas; use language that is clear, easy to understand, direct, factual and not based on opinion; and provide messages that are written in a way that youth will understand. Further, mental health content development should provide messages about mental health that are catchy and easy to relate to. Wording should be non-judgmental, neutral, have a personal tone, be sensitive, and offer youth hope.

3 Stigma

When project collaborators asked questions about barriers, they found that stigma was the primary reason youth do not look up mental health information. Youth were quite aware of the role of language and the negative impact it can have on people's lives. Mental health issues are considered taboo and remain a private issue for today's youth. More work needs to be undertaken to reduce stigma associated with mental health to improve dialogue and communication with youth. By reducing stigma, a more transparent approach can be taken to guide youth to the appropriate resources and ensure they receive adequate aid when necessary. Youth also provided a number of their own solutions such as raising awareness, normalizing mental health, and tackling the media's portrayal of mental illness, to name a few. Youth expressed that embedding mental health information into school curriculum would help raise awareness and reduce stigma attached to mental illness.

4 Credible Sites & Information

Youth demonstrate that they search for information when a problem arises or question needs to be addressed. If youth have a concern about their initial search, they will move into the next phase of exploration and start to consider what they need to do. If they determine something needs to be done, they will search information about how to seek help. Youth want to be able to find credible sites and sources of information important to them. To assist in mobilizing online mental health information toward children and youth, it may prove helpful to provide youth with a solid understanding of how to more effectively search for mental health information online and how to determine whether a site or information is considered credible (e.g. search engines). A more coordinated approach is necessary to provide youth with information on searching for credible information online, assessing and determining whether a site and the information provided on the site is trust-worthy or not, and how to act on the information they receive (e.g. help-seeking).

5 Supportive Spaces, Places and People

Outside the online environment, the research projects highlight that youth need to receive consistent and reliable information regardless of where they look for it or to whom they turn. People who are working in the education system, the health care system, community services (e.g., police, social workers, counsellors), and parents all play an important role in the day-to-day lives of youth. All of these groups need to be included to make an impact and move in a unified direction to meet youth's needs. For example, key institutions and people in a position of authority should be aware of at least one or two credible websites where youth can find information on mental health. Additionally, ensuring a good awareness level for teachers with respect to finding appropriate websites and resources would at least ensure they can effectively provide supportive direction to youth when youth are looking for mental health information or seeking help. People that youth turn to for help need to support youth in situations such as help-seeking situations or educative sessions where youth may feel vulnerable or uncomfortable talking about mental health. Spaces or places in which youth seek out information or support need to be safe and provide a sense of security.

6 The Online Environment

The online environment provides an opportunity to interact, share information, view an abundance of information and access it all through a number of convenient formats. Youth's reliance and common use of the online environment creates an excellent opportunity to provide insightful, engaging and comprehensible information on mental health. Websites such as Facebook are used regularly by many youth. Research indicates that youth prefer sites that are easy to navigate and visually engaging. Youth access a tremendous amount of information on a daily basis. Through pages and posts on Facebook, tweets on Twitter, video blogs, social media resources and other resources mentioned, youth-centric mental health information can be made available and accessible beyond settings such as school, or health care services. These sites and many others can serve as excellent gateways to building knowledge about mental health and recovery from a mental illness.

Perhaps most importantly, this report reminds key stakeholders that youth demonstrate resiliency every day. It is important that parents, teachers and community members nurture and celebrate the skills, which promote good mental health including: holistic self-care, stress management and help-seeking.

KEY RECOMMENDATIONS

Areas for action are provided to health care providers, educators, decision makers and parents to help them through online information engage children and youth in the topic of mental health. Key recommendations discussed include the following:

1. Create and identify high quality child and youth-centric mental health knowledge online

Research shows that mental health service providers should provide content in three primary areas: positive mental health or mental wellness, mental illness (e.g., myths, symptoms), and help-seeking. Content should be provided in a youth-friendly manner with credible information that is targeted to: youth who want to determine whether they are alright, youth who have a family member or a friend with a mental health problem or a mental illness, and youth who are concerned about themselves and are looking for support or help. Finally, youth want to hear from people with lived experience of mental illness—telling their stories of illness and recovery. Sharing firsthand experience will assist in reducing stigma.

2. Develop a common language that will help improve mental health literacy online

Provide youth with information that is easy to understand, credible and clearly written. Balance the use of plain language and technical or medical terminology. Provide catchy phrases and messages to which youth can easily relate.

3. Create new and exciting opportunities to engage children and youth online

Schools should be a part of the solution in disseminating information and knowledge available online, as well as educating youth on how best to use, access, and share it. Educators, health providers, and decision makers should explore applications such as Facebook and Twitter as mechanisms to inform youth about mental health. Online games including virtual worlds are also a promising path to inform youth about mental health.

4. Improve access to mental health information online

People in positions of authority (e.g., parents, educators, school administrators) should be able to recommend one or two credible and appropriate mental health resources to youth. Youth should be supported in how to act on the information they receive, which may go beyond the online environment. Mental health websites and applications should link to where children and youth can find additional help online, as well as offline.

5. Inform and build knowledge online in a way that supports the MHCC's efforts to reduce stigma

Reduce stigma by dispelling myths about people who live with a mental health problem or illness. This could be by posting a video blog or through a community campaigning effort. Help make mental health and wellness a public issue by making these topics part of a normal conversation whether at home, at school, or at play in the community.

INTRODUCTION: CHILDREN AND YOUTH ONLINE

Context

The Government of Canada established the Mental Health Commission of Canada (MHCC), an arms-length, federally funded, not-for-profit organization in 2007 in response to the findings of a Senate-generated report:

Out of the Shadows at Last – Transforming Mental Health, Mental Illness and Addiction Services in Canada (Standing Committee on Social Affairs, Science and Technology, 2006).¹ The MHCC has since developed the first mental health strategy for Canada entitled Changing Directions Changing Lives: The Mental Health Strategy for Canada. In the strategy document, Priority 1.2 highlights that children and young adults are a priority area for the Commission in promoting mental health and preventing mental illness and suicide wherever possible.

At the onset of this project, the MHCC was supported by eight Advisory Committees comprised of more than 100 experts, which included people with lived experience of mental illness. Together committee members brought a wealth of knowledge, understanding and skills to engage with a broad stakeholder community. The eight Advisory Committees each had a different focal point and guided various research projects throughout the country. The Child and Youth Advisory Committee set a mandate to engage key stakeholders (e.g., children, youth, families, educators, researchers) to learn more about online mental health content specific to children and youth.

This synthesis report is a direct result of that mandate, and it is hoped that it will serve as a catalyst to improve online engagement regarding mental health for children and youth. It is intended to provide more understanding on what youth want to know about mental health and the online opportunities that exist for engagement in a way that supports the MHCC's efforts to reduce stigma.

Please note that this study was limited in its investigation, particularly with regards to those locations where internet service is unavailable or too expensive. In addition, further study is required to fully address the population groups who face service gaps regarding their mental health needs.

Evidence Base

Research in Canada shows an 8 to 15 year gap from the time new knowledge is created to when it is used in practice (Dobbins et al. 2002). In the United States, the gap is even greater, taking approximately 20 years to integrate new knowledge or innovation into practice (Department of Health and Human Services, 2006; New Freedom Commission on Mental Health, 2003). In relation to child and youth mental health knowledge development and integration in practice a number of strategies have been undertaken. However, very little empirical evidence is available on their effectiveness; thus, a substantial disconnect remains between what is known as effective practice and what is carried out in practice (Harrington et. al., 2009). Policy makers, educators, researchers and service providers need more research to help guide their decisions regarding the best media, strategies and/or interventions to improve children's, youth's and parents' knowledge of mental health (Lal, 2009).

The societal and personal consequences of stigma are well documented. For example, stigma at the societal level includes rejection, discrimination and harassment. At the personal level, self-stigma can result in social isolation, poor self-image, denial of one's condition, as well as poor help-seeking, coping and behaviours. Moreover, stigma is often

¹ For more information, please refer to: http://www.mentalhealthcommission.ca

² For more information on past Advisory Committees, please refer to: http://www.mentalhealthcommission.ca

neglected when knowledge exchange strategies are undertaken. Research indicates that sometimes information that is meant to educate children, youth and parents can result in negative attitudes, behaviours and stigma, particularly when it is poorly presented (Schachter et al., 2006). It is important to distinguish what kind of information is available and how the messages are perceived by youth, so that stigma is diminished rather than increased.

Projects

This document is a synthesis of three project reports that were undertaken by the Mental Health Commission of Canada, and championed and overseen by the Child and Youth Advisory Committee.

Cathexis Consulting utilized a mixed methods approach to collect quantitative and qualitative data through online surveys (N=248), interviews (N=31) and focus groups (N=27) from a total of 298 diverse youth across Canada aged 12 to 18 (Cathexis, 11). These youth provided considerable in-depth insights with respect to what youth want to know about mental health, how they search for mental health information, and the barriers to acquiring information. Results focused on youth perspectives on mental health, how they talk about mental health, the role of language in stigma, and the preferred terms or language that should be used to talk about mental health.

Project collaborators from mindyourmind—a not-for-profit mental health program that engages youth—utilized a qualitative data collection method⁴ to acquire information from 21 youth, including 5 male and 16 female participants who were between the ages of 12 and 18. Four focus groups included participants across Canada including Western Canada, Ontario and Eastern Canada. Mindyourmind collected information about age, gender and province of residence. Participants varied in other characteristics including cultural background, but this information was not formally collected. In the focus groups, youth were asked about: their perceptions of mental health, who they turn to for help, stigma and their experiences with social media technologies (e.g. their preferred modes/mediums for receiving youth-centric mental health information).

Finally, a literature review by Shalini Lal focused on the online environment, which provides an opportunity to move beyond traditional media formats (e.g., print materials) in a way that has the potential to meet youth where they are at (e.g., in the home environment, on their smart phone as they walk to school). Additionally, the information can be tailored to their needs, developmental stage, interests, learning style, as well as in a way that expands the reach of mental health knowledge dissemination to youth. This review identifies the key characteristics that make social media channels, applications and sites popular among youth. It also provided some brief examples of which health-oriented sites are popular, and how social media applications and sites are used in health promotion initiatives.

The results from all three projects culminate in an initial foundation for the ongoing development of an online knowledge mobilization strategy for child and youth mental health. Due to the complementary nature of the projects, the results have been synthesized and organized by six primary topics: (1) mental health content; (2) language; (3) stigma; (4) credible sites & information; (5) supportive spaces, places & people; and, (6) the online environment. The intent of this synthesis report is to provide health care providers, educators, decision makers and parents with recommendations (that flow from the above-mentioned projects) to engage children and youth with current and interesting mental health information online. It is also intended to inform organizations on how to reach youth via their websites with the kind of information adolescents require.

³ Ethics approval was received from the Sudbury District Health Council Research Ethics Board.

⁴ Ethics approval was received from the University of Western Ontario's Research Ethics Board.

1 MENTAL HEALTH CONTENT

The consultants asked youth about a number of topics that relate to the development of mental health information. This section provides a summary of youth's responses to: (1) what they want to know about mental health, (2) whether or not they look for mental health information and (3) how they understand mental health.

WHAT DO YOUTH WANT TO KNOW ABOUT MENTAL HEALTH?

We found that youth want to learn about three specific content areas: positive mental health or wellness, mental illness, and help-seeking and accessing mental health services. When we asked youth in surveys (N=248) about what they wanted to know about mental health there was some variation (Cathexis, 11). Most youth (76%) wanted to know how to tell if they are alright or if a family or friend needs help (71%). Youth also wanted to know what mental health is (70%). Fewer wanted to know what to do if he/she needed help (59%) and even fewer wanted to know who to talk to (29%).

These trends were fairly consistent across age and gender, although a much higher percentage of younger males aged 12 to 15 (91%) than younger females aged 12 to 15 (43%) wanted to know how to tell if they are alright. Among the older male youth age 16 to 18, 'what mental health is' and 'how to tell if I am alright' were ranked highest; females ranked 'how to tell if I am alright' and 'what to do if a family member or friend needs help' highest.

During the interviews (N=31) and focus groups (N=27), youth were able to provide in their own words what they wanted to know about mental health. While there was some variation, youth provided greater depth and rationales behind their thought process (Cathexis, 7).

YOUTH WERE INTERESTED IN LEARNING MORE ABOUT:

- · How mental health and mental illness are defined.
- · What qualifies as mentally healthy and mentally ill.
- What the different types of mental illness are.
- What the causes of mental illness (e.g., biology, chemical imbalance, feeling stressed out, lack of sleep, whether friends/family constantly 'putting a youth down' contributes to mental illness, stress) are.
- What the signs, symptoms and severity of the different mental illnesses are.

- · What the stages and progression of mental illness are.
- Why some people get mental illness and others do not.
- What the difference between mental illness and going through a difficult time is.
- Whether mental illness can be transferred to a foetus during pregnancy.
- · What the impact of mental illness on one's life is.

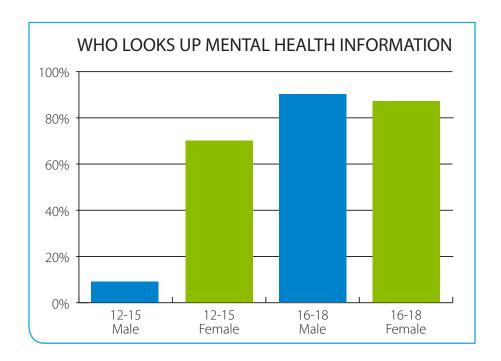
Other youth wanted to know how to cope with mental illness and to gain insight or to grow as a person with a mental illness. Some youth also noted they were interested in learning more about how mental illness could be prevented, as well as how to support people's mental health. Some youth in another focus group were interested in having more information that is focused on dispelling some of the myths and stereotypes about mental illness. Some queries included: 'if you tell people you are not mentally well, will they place you in an asylum?', or 'are mentally ill people dangerous?', and 'is mental illness the same as having Down's Syndrome, Alzheimer's or Parkinson's disease?'

OTHER YOUTH HAD QUERIES ON HELP-SEEKING:

- What different kinds of help are out there for me?
- As a teenager and dependent, how can I get that help?
- What is the medical coverage for things like therapy and medical treatment?
- How do I get help when the person I am seeing for help is not listening to me?
- How does one get a diagnosis of mental illness?
- How can I get help without having to identify myself?

DO YOUTH LOOK FOR MENTAL HEALTH INFORMATION?

Youth were also asked in a survey format whether or not they searched for mental health information. We found that responses of youth varied by age and gender. For example, among the younger youth age 12 to 15 interviewed (N=4 in the younger age group) and surveyed (18 in the younger age group, females [71%] were much more likely than males [9%] to have looked up mental health information (Cathexis, 11]). Whereas with the older age group, there was no appreciable gap among the males and females; approximately, 90% of males and 88% of females age 16 to 18 reported that they searched for mental health information.



Some of the youth in focus groups indicated that they had not thought about mental health or wellbeing until something happened. Survey respondents also indicated that they were generally able to find the information they needed when seeking information about mental health. The few respondents who had trouble finding information indicated it was often confusing or not helpful for their needs.

HOW DO YOUTH UNDERSTAND MENTAL HEALTH?

Both the Cathexis and mindyourmind research projects found that the youth's use and understanding of the term 'mental health' was focused on mental illness. For example, a majority of youth associated the term mental health with mental illness. And, despite using the terms 'mental health and mental wellness' during the interviews (N=31) and focus groups (N=27), youth heard, framed and talked about mental illness when referring to mental health (Cathexis, 22). It was not until there was discussion about the health and wellness that the youth started to recognize the positive domain of mental health.

Youth also frequently noted that mental health is tied to physical health, indicating that if you are not physically healthy and do not feel confident, then you can feel depressed or uncomfortable. Youth considered this to be something that is fairly common among their peers. Several youth also indicated that sleep and diet can have an impact on mental health. Other youth noted the importance of the connection between the mind and body, and that mental health may be linked to one's emotional state. They also noted that having a mental illness may affect one's mental health, but one is not necessarily the same as the other (i.e. not interchangeable). Some youth also expressed that mental illness is not a person's fault, but often something with which they were born. Some youth recognized that people do not choose to have a mental illness.

We found in the focus groups (N=21) that younger youth aged 12 to 14 (N=5) were not familiar with the clinical terms or definitions of mental illness (mindyourmind, 13). The terms they used were in plain language, such as 'feeling like everyone is against you' or 'someone who needs help'. The younger youth also equated mental illness with developmental disorders. Older youth aged 15 to 18 (N=16) were more familiar with terms such as anxiety or depression to talk about mental illness. Youth indicated that mental illness is a difficult problem; it is hard to 'see' or identify. In comparison to physical health, mental illness is harder to understand or discuss with others.

SUMMARY NOTES - MENTAL HEALTH CONTENT

Youth think about mental health, and have acted on their desire or need to learn about the general topic. The results above also highlight the need to provide mental health content to youth that includes three primary domains of information: (1) positive mental health or mental wellness, (2) mental illness (e.g., myths, symptoms), and (3) help-seeking. Youth look for mental health information, and even more so in the older age group. Additionally, mental health content development should incorporate three youth audiences: (1) youth who want to determine whether they are alright, (2) youth who have a family member or a friend with a mental health problem or a mental illness, and (3) youth who are looking for support or help for themselves. Often a needs-driven approach determines how youth use mental health information, so mental health content should be created in a way that meets those needs. In general, more research would be helpful to understand whether what youth want to know about mental health and how they search for information is divergent from what adults are seeking.

2 I ANGUAGE

We were interested in learning more about how youth talk about mental health, as well as what terms should be used to talk about mental health with youth. Provided below are the results of the project collaborators' discussions with youth about mental health.

How do youth talk about mental health?

From the interviews (N=31) and the focus groups (N=27) undertaken by the project collaborators, we found that youth used terms like 'emotional problems', 'mental problems', 'mental functioning', 'mental stability', 'mental disorders', 'mental health diseases', 'mental health troubles', 'mental', or 'mentally challenged' (Cathexis, 20). Some youth also used technical or medical terms to talk about mental health such as schizophrenia, depression, bipolar disorder, and multiple personality disorder. Many youth also used the terms 'crazy' and 'insane' when describing and discussing mental health, and they noted that people who were 'crazy' are not part of the norm. Other terms that were used include:

- Psychologically sane
- Calm and peaceful
- Relaxed
- Strong individual
- Healthy and happy
- Normal
- Wellness
- · Emotional health
- Sanity

- Someone who needs help
- State of mind/mood
- Chemical imbalance
- Misunderstood
- In a bad space
- Depressed
- Disorders
- Head case
- Feeling like everyone is against you

- Stressed out
- Nut case
- Disability
- · Emotional problems
- Self-harm
- Stupid
- Hindrance
- Suicidal thoughts
- Homelessness

In addition, some youth used the term 'mental wellbeing'. When asked what this meant they stated that they perceived it to be the ability to 'communicate and function without being hurtful to themselves or others; not being stressed out.' The term 'mental health' was frequently associated with stress. In other cases, the youth attributed stress to factors such as, family situations or problems, or to school. One youth also noted the impact of cultural stress on mental health and how different cultures within Canada have different ways of addressing stress.

What terms or language should be used to talk about mental health?

When youth in the interviews (N=31) and focus groups (N=27) were asked about the terms and language that should be used there was variation (Cathexis, 20). Some youth indicated that there needed to be differentiation between the terms 'mental health' and 'mental illness', as the latter has a negative connotation. Other youth noted the importance of using proper technical or medical terminology, including the names of the different mental illness. These youth felt that putting a name to someone's illness or symptoms, and providing a diagnosis, can be a step towards recovery because it confirms that there may be a problem that can be addressed and a possibility of moving towards stability. Others indicated that words like 'unstable' also offer the connotation that things can change (Cathexis, 14).

Several youth indicated they did not believe that specific terms should be used because they label the individual as being different. Youth felt that using technical or medical terminology can reduce people's understanding of mental health problems and may alienate people living with a mental illness. Other youth suggested avoiding the use of the term 'mental illness' since it has the potential to make people 'feel bad'. Other youth who were interviewed indicated that they did not like, or agree with, the use of the word 'crazy'. They stated that people with a mental illness are not really crazy. Another word that some youth felt should be avoided is 'abnormal', as it has a negative connotation. Instead, youth expressed that it would be better to use the word 'condition' because it is a less negative term. Youth also suggested that the medical/scientific terminology would be more appropriate for an older audience.

LANGUAGE USE AND MESSAGING FOR WHICH YOUTH ARE LOOKING:

- Language that is factual and is not simply based on opinion
- Positive language that offers the message that you are not alone and that help is available
- Language that is clear and easy to understand
- Simple and direct language that does not mix several concepts together
- Language that is neutral, non-judgmental, and sensitive to the subject

- Language to which youth can relate
- Language that express a sense of hope
- Words and phrases that are catchy so that youth remember them
- Language that is relevant
- Language that is simple—content written in plain language.

Summary Notes - Language

With respect to language use in relation to mental health, we found that there was debate about which terms should be used and how to talk about mental health. That said, youth indicated that the mental health content needs to:

- Balance the use of plain language and technical or medical terms;
- · Describe distinct concepts and ideas (e.g., mental health, mental illness and the different mental disorders);
- · Use language that is clear, easy to understand, direct, is factual and not based on opinion; and
- Provide messages that are written in a way that youth will understand.

Mental health content should provide messages that are catchy and easy to relate to. Wording should be non-judgemental, neutral, have a personal tone, be sensitive or offer youth hope (e.g., that they are not alone and that help is available). The language used to talk about mental health is often geared to adults and not meant for a youth audience, their developmental stage or learning style.

3 STIGMA

When the project collaborators talked with youth about mental health, they asked them about what impedes their search for information about mental health. Stigma was mentioned as a primary barrier to searching. Presented below is a discussion focused on the different responses from youth about this topic as well as a suggestion of raising awareness.

What factors impede youth's desire to search for mental health information?

When youth were asked in the interviews (N=31) and focus groups (N=27) about 'what stops them from seeking information about mental health', youth cited a lack of mental health information, and that when the information is available it is difficult to understand (Cathexis, 23). Further, much of the posted information online is not for them; rather, it is geared towards adults. In other cases, youth did not search or look for information because they felt that the topic or issue is not relevant to their direct situation. Other youth felt that they did not search for information because they considered the topic itself depressing and not something that they were interested in discussing with others.

More specifically during the focus groups, when asked about barriers to seeking out mental health information, stigma was a primary concern. For example, many of the youth indicated that the subject of mental health is taboo. Youth noted that mental health is not something that people are comfortable discussing. Youth stated that they have a fear about being stigmatized if they search for mental health information. They felt they may be judged or pushed away by others, or labelled as being different. Youth cited that generally, 'people are scared of things that they do not understand', and through a lack of accessible information, mental health continues to be negatively portrayed within society, and by the media.

Interview participants provided responses similar to the focus groups participants. Youth who were interviewed offered a range of reasons for why they hold back from looking for more mental health information. The first reason was fear of being labelled; in particular the term 'crazy'. To label someone was off-putting to them, and for this reason, youth avoided searching for mental health information. They also noted that youth may avoid accessing mental health information because it would cause them to feel embarrassed or uncomfortable, in particular when discussing one's own mental health. During several interviews, mental health was described as being a private topic, and not a normal subject of conversation.

Another reason youth do not search for information stems from how people with a mental health problem or a mental illness are treated, which the youth perceived to be negative. For instance, some of the youth indicated that at their school, students with 'special needs' are bullied by other students. Students make jokes about mental health, and in particular jokes about something being wrong in a person's brain.

Raising Awareness

In general, many youth also felt that the subject of mental health, and living with a mental health problem, is linked to a negative perception of mental health. They noted that negativity surrounding mental illness is related to people not understanding it in the same way physical illness is understood. Several youth felt that others often see mental illness as being the person's own fault. They noted that 'people focus on the negative aspects of mental health because it is more interesting to talk about, than good mental health.' As one youth stated "you never hear of people saying: 'oh my god, I have great mental health'."

Several youth also noted that in order to get past the stigma, it is important to raise awareness and educate people about mental health, what factors may alter a person's mental health, what symptoms may be associated with the different mental illnesses and what are some of the experiences of people living with mental health problems. They indicated that it is important to stress that there is nothing 'wrong' with individuals who are dealing with a mental health problem, and that it is alright to be interested in mental health.

With respect to language use and stigma, both project collaborators found that many of the youth they talked with demonstrated an awareness of language as a means of exacerbating stigma. For instance, in the interviews (N=31) and focus groups (N=27) they found that the response of youth clearly showed an understanding of the negative impact of language on our perceptions of people (Cathexis, 22). In one focus group, youth indicated that the wording used when speaking about mental health is important because certain words may offend based on their meaning. They stated that some words should be avoided because they are steeped in negative connotations, and they are considered by youth to be an effort to dismiss the topic of mental health and/or insult individuals who may be living with a mental illness.

Several youth also indicated that it is important to change the public's negative perceptions regarding mental health. They felt greater work needed to be carried out with the media because it influences peoples' understanding of mental health. For instance, in one interview the youth provided an example from an episode of the show *Degrassi* where a youth went 'crazy' by driving a car into a wall when he was dealing with a mental health problem. This youth noted that the association of the word 'crazy' with mental health is related to the media's portrayal of mental health.

Additionally, youth felt that schools do not do a good job of addressing stigma. They noted that schools could help by decreasing stigma associated with mental illness by increasing awareness. Suggested ideas from the youth include embedding mental health-oriented information into the curriculum, as well as placing this information throughout the school setting.

Summary Notes - Stigma

When the project collaborators asked questions about barriers, they found that stigma was the primary reason youth do not look up mental health information. Youth were quite aware of the role of language and the negative impact it can have on people's lives. They also found that youth did not formally use the term 'stigma' in their talk about mental health. Mental health issues are considered taboo and remain a private issue for youth. Through a lack of information and potentially misinformation, mental health remains a subject somewhat distant from today's youth. Greater work needs to be undertaken to remove the stigma associated with mental health in order to improve dialogue and communication with youth. By minimizing stigma, a much more transparent approach can be taken to guiding youth to the appropriate resources and ensuring they receive adequate aid when necessary. Youth also provided a number of their own solutions such as raising awareness, normalizing discussions of mental health, and tackling the media's portrayal of mental illness, to name a few. Youth also thought that enhancing the school curriculum with mental health information would help to raise awareness and reduce the stigma attached to mental illness.

4 CREDIBLE SITES & INFORMATION

This section explores the preferred ways youth would like to receive mental health information. In the mindyourmind focus groups (N=21), one issue that youth discussed involved how to find mental health information online. Finding credible sites and mental health information that was geared to a youth audience did not always prove easy. Focus groups revealed that some youth knew how to find mental health information online, while others demonstrated less knowledge. For example, some youth considered sites such as Canadian Mental Health Association, mindyourmind and Health Canada as credible, while others were not aware of these sites.

What are the preferred ways youth would like to receive mental health information?

The majority of youth in the interviews and focus groups indicated that they would use the internet, and in particular Google, to search for mental health information. Youth noted that they focus on the first group of sites that come up, and are more likely to seek out government websites such as Health Canada's website http://www.hc-sc.gc.ca/index-eng. php or other websites like www.KidsHelpPhone.ca and www.depressionhurts.ca. Youth search these sites because they trust the information on an official website like Health Canada more than information posted on someone's blog. That said, the youth noted that the information on these sites can be quite 'vague' and 'difficult to understand'.

Additional sites youth use include WebMD, Centre for Addiction and Mental Health, Wikipedia and You Tube, the latter because it grabs their attention. Some youth also access online forums for information-gathering. Online forums provide one way for youth to share their feelings and talk with others about mental health. They like the anonymity of the online forums, and they provide opportunities for the youth to feel as though they can fully express themselves.

Youth indicated that certain sites, despite being regarded around the country as an authoritative source of mental health information, were sometimes not preferred because the text is too dense. Broadly speaking, these youth indicated they do not want to read dense text. They want to receive information that 'gets to the point'. They also indicated that the material must be engaging: 'If it's not interesting online, I don't want to read about it.'

Among youth, videos were the most widely mentioned and preferred modality to receive mental health information. That said, there were a few caveats. Youth indicated videos must be 'interesting', which some perceived as involving humour. They must not be overly long. As one participant described it, they should be 'about the length of a song.' They prefer watching celebrities talking about mental illness, or peers who have experienced and found ways to manage it. Watching videos featuring psychologists or other authorities did not interest youth. In addition, youth noted that once online sources were developed, they should be advertised in a number of ways: on television, in school through teachers and counsellors, and on sites such as Google and Facebook.

Youth in the interviews (N=31) and other focus groups (N=27) noted that they would appreciate information that incorporates real-life and positive examples of people who have had a mental illness and have managed to live stable and happy lives (Cathexis, 30). Many indicated they would like firsthand stories about how mental health affects day-to-day life, as opposed to extreme situations. Others would like to receive mental health information that is fact-based rather than opinion and they would like information that they 'can relate to'. These youth noted that they would like to receive information through people they know, historical figures or celebrities who have lived experience of mental illness, or from people who are credible. They would like this information disseminated through their networks by someone they know and trust, a mental health expert or a person with lived experience of mental illness. Moreover, youth in this project noted that many websites offer general information, but they would like to see sites that have

information that is more personal and provides all the information in one place. They would also prefer interactive sites with message boards for sharing information and stories, a chat function to communicate with other people on the site and/or a function that allows questions to be asked and then answered by experts.

Serious games, or games that provide educational material, were perceived as acceptable, but only in certain cases: 'If I'm trying to find information for my friend, I don't want to play a game.' Games that present coping mechanisms, such as ways of handling stress, were satisfactory to some youth. Short, fun quizzes about mental health were also discussed. Again, the youth would like to receive these in interactive format and '[t]hey should be less than 10 questions. Otherwise, I would think, "I could be on Facebook by now".' Some participants thought Facebook apps for mental health information would be useful, but others would not want to interact with mental health apps on Facebook because their friends would then know about it.

Several youth also noted that information available online should be easy to access and that the website should be easy to navigate. The site should cater to youth aesthetically, meaning that it should use colours and fonts that are not reminiscent of a medical office or exam room but are vibrant and catch the eye of youth.

Youth's Searching Techniques

In relation to how youth search for mental health information, often youth do not extend their search beyond their initial query. Youth tend to search for information by including all relevant keywords in the search box to help narrow down the number of sites that surface. Several youth also indicated that they search by asking a question such as: 'how do I improve mental health?'; 'how do I deal with mental health?'; or 'how do I prevent poor mental health?'.

The general search pattern youth followed is a natural progression of inquiry. For example, youth ask about mental health by first 'checking things out' and by asking the question 'is there a problem?' At this stage youth want to determine: 'what is mental health?'; 'how do I know I am doing okay?' and then figure out 'what is normal or what does normal look like?' Youth will also consider 'is what I am experiencing part of life?', or 'is this something I should look into further?' If youth are positively validated, and determine that 'yes, I am okay' they will conclude their search.

However, if they are still concerned or a red flag is raised during the first step, youth will move into the next level of exploration. At this point, youth are starting to consider 'what do I need to do?' and begin to look for tactical, instructive, information. They are looking for guidance about 'what steps or actions they could take', and quality solutions in a format that is easy for them to access and understand. They want to know more about the symptoms of mental illness. They are looking for reassurance, and are trying to determine 'what can I do to feel better?'

Once a youth has determined that something needs to be done, the third stage centres on help-seeking. For example, youth begin to search for information about: 'where can I go to get help?'; 'what can I expect if I take this step?'; and, 'what do I need to know about treatment options?' This group is most likely to include at-risk youth.

How do youth obtain detailed mental health information?

When it comes to the ways in which youth use mental health resources, we found that youth use resources when they are directly related to the information they are seeking.

MOST COMMON REASONS FOR ACCESSING RESOURCES REGARDING MENTAL HEALTH WERE:

- Finding the name of an illness that explains their symptoms
- Learning about the symptoms of a mental illness
- Learning about why some people have a mental illness and others do not
- Determining whether they or someone they know may have a mental illness
- Learning about medication
- Finding mental health organizations
- Finding information that explains what people with a mental illness are going through

- Gaining an understanding of what they are dealing with so that they can be supportive
- Finding strategies to help them cope with how they are feeling
- Finding tests posted online to help youth determine if they are depressed
- Finding ways to deal with stress
- Feeling that 'they are not alone' and that other people have gone through a similar experience; and
- Determining whether what they are feeling is 'normal'

On the whole, the youth indicated that they used the resources they found in a number of ways, including to address questions of personal interest, to seek support in dealing with their own mental health problems and to complete school assignments.

How do youth find credible sites or information about mental health?

During focus groups (N=21), some youth did not know what qualities to look for when searching for information online (mindyourmind, 15). In addition, not all youth trusted the information posted on a site, emphasizing that it can be difficult to determine whether the information posted on a site is in fact credible. In the words of one youth: "I looked for 'bipolar' on the internet and thought I was going to die in seven days."

Youth were quite interested in acquiring information from credible sources and believed sites with a .org, .gov, or .ca domain suffix provided a clue into whether a site was potentially credible for acquiring online information. However, many of the youth were aware of the ability to change information online.

Researchers also found that youth's perceptions of what were 'credible sources' are related to: writing style on the sites, whether the site was referred by a trusted adult, or if it was a page with many visits. With respect to seeking information online versus 'offline', some youth in the focus groups indicated that they trust authoritative figures such as doctors more than they trust online information.

There were a few red flags with respect to the information revealed through the focus groups. Researchers were concerned about youth's level of knowledge with search engines. While youth discussed that they knew how to use Google, there was less recognition regarding how materials get posted online and how search results are listed. Researchers raised a concern that some youth participants trusted and were satisfied with information they find on sites such as 'Yahoo! Answers.'

Summary Notes - Credible Sites and Information

Youth demonstrate that they search for information when a problem arises, a question needs to be answered or they have a school project. If youth are concerned about their initial search, they will move into the next phase of exploration and start to consider what they need to do. If they determine something needs to be done, they will search for information about how to seek help. Youth use the information most frequently when it is directly related to the information they search for. The issue of youth being able to find credible sites and sources of information is important to youth. Additionally, it is crucial for the next stages of help-seeking, since youth may not know where to turn next if a site and its information is not credible.

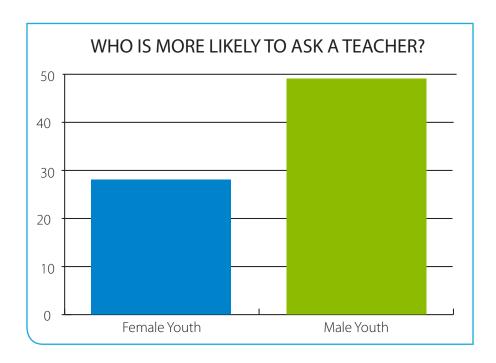
The problem of how to determine whether a site and its information are trustworthy, as well as how to use search engines more effectively are persistent issues. Parents, educators and youth each play an important role in assisting to mobilize online mental health knowledge. For example, parents and educators should stay engaged with youth and the information youth search for. To assist in mobilizing online mental health information toward children and youth, a more collaborative approach would be effective in assisting youth to find the credible sites and information they require.

5 SUPPORTIVE SPACES, PLACES AND PEOPLE

Another focus of these projects was to explore where youth go to find information about mental health beyond the online environment and to whom they turn for support.

Beyond online: where do youth go to find information about mental health?

Youth look for mental health-oriented information from a wide range of sources. For example, two-thirds of males and a third of females seek out information in a library or magazine. Youth also seek out information from other people (e.g., teacher, nurse, school counselor or psychiatrist). According to research (29%) of females and (49%) of males went to a teacher for information (Cathexis, 25).



With respect to help seeking on the part of youth (N=21), we found youth were more likely to turn to a sensitive, non-judgmental, person in their life (mindyourmind, 15). Youth indicated that their help seeking was connected to their relationship with an authoritative person in their life. For example, going to parents for help about mental health problems depended upon how close the youth were to their parent(s).

Teachers and counsellors in the school setting were potential options for youth, but that was contingent upon the extent to which the student felt the teacher or counsellor was ready to listen. In some cases, youth felt that talking to a general practitioner about a mental health problem would be a comfortable situation, while other youth felt that general practitioners are primarily interested in prescribing medication and then moving on to the next patient. There was a general concern that if the people youth go to for help are not trustworthy, they will judge the youth for having a mental health problem.

Many of the youth also felt that people who have been through mental illness would be a reliable source for information. In the words of one youth: '[t]hey're the only ones who understand'. Youth felt that talking to a stranger was concerning so they were more likely to talk with someone they know.

Pamphlets or posters were considered to be potential sources of information especially in places where youth spend their free time. Youth spend time watching television, Netflix or YouTube, and listening to the radio. They also spend time in malls, movie theatres and at friends' houses so mental health information could be provided in such settings through kiosks in the mall or informational advertisements in movie theatres. Youth often reported having seen ads for online/telephone crisis lines on candy wrappers and television.

Summary Notes - Supportive Spaces, Places and People

Outside the online environment, the research projects highlight that youth need to receive consistent and reliable information regardless of where they look or to whom they turn. People who are working in the education system, the health care system, community services (e.g., police, social workers, counsellors) and parents may all play an important role in the day-to-day lives of youth. Researchers recommended that all of these groups collaborate in order to ensure good awareness of mental health information that can meet youth's needs.

It is advisable that people in positions of authority (e.g., parents, educators, school administrators) should be able to recommend one or two credible and appropriate mental health resources to youth. Additionally, the people youth turn to for help need to support youth in situations such as help-seeking where youth may feel vulnerable or uncomfortable, and where youth are not able to seek help on their own. Spaces or places in which youth seek out information or support need to be safe and provide a sense of security.

6 THE ONLINE ENVIRONMENT

Shalini Lal conducted a literature review and environmental scan of popular social media sites and their relevance to a knowledge mobilization strategy in child and youth mental health. Lal (2010) focused on the following key areas including: what makes social media channels, applications and sites popular with youth; which social media channels, applications and sites are popular with youth; and how social media applications and sites are used in health promotion initiatives.

Briefly, the online environment has become incredibly popular with youth because it provides an opportunity to interact, share information, view an abundance of information and access it all through a number of convenient formats. Youth have embraced the online environment as a way of communicating, connecting and seeking information. This reliance and common use of the online environment creates an excellent opportunity to provide insightful, engaging and comprehensible information on mental health.

Online social networks such as Facebook are used regularly by a strong majority of youth. Youth process or access a tremendous amount of information on a daily basis. Through pages and posts on Facebook, tweets on Twitter, video blogs and other resources mentioned, youth-centric mental health information can be made available and accessible beyond settings such as school, or health care services through the use of the most popular social media applications and sites. Applications are convenient for youth and they appreciate their simplistic and user-friendly layout. Research indicates that youth prefer sites that are easy to navigate and visually engaging. Thus, in order to ensure the information is received properly, it must be communicated in a youth-oriented manner.

In addition, games have become a potential outlet for mental health awareness or service provision. Games are already built in a way that requires youth to operate or interact as if they are involved in an everyday setting. In the virtual work, for example, youth can be taken through a scenario where they have to cope with mental illness, or figure out how to acquire help or advice from avatars that are health professionals. A virtual game can integrate a mental health focus as part of the overall plot.

Furthermore, the online environment provides an opportunity to move beyond traditional media formats (e.g. providing information in print materials in a setting such as schools) in a way that has the potential to meet youth where they are at (e.g., in the home environment, on their smart phone as they walk to school), tailor information to their needs - developmental stage, interests, learning style, as well as in a way that expands the reach of mental health knowledge dissemination to youth. The online environment supports the information needs of youth by offering a number of benefits to the youth such as the privacy that comes with accessing information from a home computer or smart phone, and in a setting of their choice. Youth can also devote as much time as they would like to gathering information, and they can learn about mental health in as much detail as they choose. The online environment affords youth the opportunity to access information in a way that fits with their interests, needs or approach to learning. It offers flexibility, convenience, and accessibility from different geographical locations (e.g., rural, urban). Youth can also explore the topic without the fear of being stigmatized or labelled. The online environment can be used as a mechanism to enable youth, or support youth, as they seek out mental health information on their own.

However, the online environment also causes some concern as a mechanism to disseminate mental health knowledge for youth. Internet addiction has been documented in the literature as a serious health concern for youth (Kim et al., 2006). Thus, it may be important to consider the extent to which engaging youth in mental health-related content through the internet might actually perpetuate excessive internet use. Other concerns pertain to issues of privacy and using personal information for commercial purposes, as well as copyright issues and maintaining information-oriented updates and quality. Vandalism or hate campaigns and bullying (online/offline) are also concerns that have been raised.

Additional concerns include: accessibility for all youth, exploitation of youth and issues related to quackery (Boulos et al., 2007). Moreover, social media trends are rapidly changing and evolving. What is popular today may not be popular one year from now. Continuous exploration of new and innovative ways to use social media is important in order to reach more youth in need of mental health support.

Summary Notes - The Online Environment

The online environment offers an important opportunity to post relevant materials for youth, as well as a space for youth to access mental health information. Websites offer a number of convenient formats and are excellent tools to build knowledge about mental health and recovery from a mental illness. Research shows that Facebook and Twitter are popular among many youth, as youth prefer interactive sites that are easy to use and visually appealing. Mental health information intended for children and youth should be communicated in a youth-oriented manner. Beyond the school and health settings, social media applications and sites offer a tangible way to bring mental health support and resources to children and youth.

RECOMMENDATIONS

Gathering what we learned from the three projects, the following recommendations should be considered when undertaking an online child and youth mental health knowledge mobilization strategy.

1. Create and identify high quality child and youth-centric mental health knowledge online.

- Provide content online in three primary areas: (1) positive mental health or mental wellness, (2) mental illness (e.g., myths, symptoms), and (3) help-seeking.
- Provide information to youth in a user-friendly manner with credible information on websites.
- Incorporate information targeted to three youth audiences: (1) youth who want to determine whether they are alright, (2) youth who have a family member or a friend with a mental health problem or a mental illness and (3) youth who are concerned about themselves and are looking for support or help.
- To reduce stigma, include people with lived experience of mental illness telling their stories of illness and recovery, and whenever possible have people with firsthand experience also deliver literacy information.

2. Develop a common language that will help improve mental health literacy online.

- Provide youth with information that is understandable, credible and clearly written
- Create content that provides a balance between the use of plain language and technical or medical terminology; and,
- Provide catchy phrases and messages to which youth can easily relate (e.g., use non-judgemental, neutral wording that is personal in tone, offer youth hope while acknowledging they are not alone).

3. Create new and exciting opportunities to engage children and youth online.

- A knowledge exchange strategy online should include people who are working in the education system, the health care system, community services (e.g., police, social workers, counsellors), as well as parents. A coordinated effort will enable people involved in various mental health, research and advocacy programs to act on a local, regional, national and global level to help alleviate the stigma and discrimination that is too often associated with mental health problems and illness.
- Youth suggested incorporating mental health information into school systems and curriculum. With
 various technologies being introduced and utilized in the classroom, schools should be a part of the
 solution in disseminating information and knowledge available online, as well as educating youth on how
 best to use it, access it, and share it.
- Educators, health providers, and decision makers should continue to explore applications such
 as Facebook and Twitter as a mechanism to inform youth about mental health. Youth enjoy these
 applications because they provide an opportunity for interaction, collaboration, flexibility and
 participation. Facebook can be used as a mechanism to disseminate mental health information.
 Informative pop-ups or advertisements, mental health content, and where to access mental health
 services can all be posted on Facebook. Twitter can also be used in a similar format. Regular tweets about
 mental health information are a great way to engage youth.

Online games are another avenue to inform youth about mental health. For example, virtual worlds
can teach youth about the importance of mental health and making healthy lifestyle choices. Some
initial work has been undertaken in relation to improving people's knowledge of mental health, as well
as approaches that focus on the treatment of mental illness such as phobias, depression and anxiety.
The general mental health community could explore the use of virtual social worlds as a mechanism to
educate youth. This medium could improve their ability to recognize the signs of mental health problems
not only in others but also in themselves.

4. Improve access to mental health information online.

- It is advisable that people in positions of authority (e.g., parents, educators, school administrators) be able to recommend one or two credible and appropriate mental health resources to youth.
- Further, people in positions of authority can assist youth in their search for credible sites and trust-worthy
 sources of information online. For example, people in positions of authority (e.g., parents, educators,
 school administrators) could teach youth about new and exciting ways to utilize search engines, explain
 how materials are posted online and how search results are listed in order of most frequently visited,
- Let youth know how to act on the information they receive and explain that they have various options in seeking help beyond the information posted online.
- Mental health websites and online engagement tools should link to where children and youth can
 find help online, as well as offline help within the mental health community and alternative sources of
 assistance.

5. Inform and build knowledge online in a way that supports the mhcc's efforts to reduce stigma.

- Reduce stigma by dispelling myths about people who live with a mental health problem or illness. This
 could be by posting video blog or through a community campaigning effort.
- Help make mental health and wellness a public issue by making these topics part of a normal conversation whether at home, at school, or at play in the community.

Final Remarks

The three projects summarized within this synthesis report were undertaken by the project committee of the Mental Health Commission of Canada's Child and Youth Advisory Committee whose mandate was to engage key stakeholders such as children, youth, families, service providers, policy makers, educators and researchers in the ongoing development of an online knowledge mobilization strategy for child and youth mental health. This synthesis report provides the initial groundwork for health care providers, educators, decision makers and parents to get inspired about the ways we all can share in helping to advance quality child and youth-centric mental health knowledge online. It is up to adults to educate themselves about online mental health information and actively listen to child and youth voices, particularly those who have lived experience of mental illness. With the foundational work laid, the task before us is to ensure that mental health information is successfully communicated to youth in ways that are applicable, easy to understand and use. We hope that this report will prompt more discussion and serve as a catalyst for the promotion of mental health knowledge mobilization online for children and youth throughout Canada.

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