Electronic Thesis and Dissertation Repository

4-18-2016 12:00 AM

Accessibility and Self-disclosure of the Journey Through Mental Health: Youth Sharing Their Lived Experience

Caryl-Anne Stordy, *The University of Western Ontario*

Supervisor: Dr. Susan Rodger, *The University of Western Ontario*
A thesis submitted in partial fulfillment of the requirements for the Master of Arts degree in Education
© Caryl-Anne Stordy 2016

Recommended Citation
Stordy, Caryl-Anne, "Accessibility and Self-disclosure of the Journey Through Mental Health: Youth Sharing Their Lived Experience" (2016). *Electronic Thesis and Dissertation Repository*. 3703.
https://ir.lib.uwo.ca/etd/3703

Abstract

Using the lived experiences of youth in Southwestern Ontario, the current project explores the decision of youth to self-disclose their status of mental illness and disability. To explore the process of disclosure, three research questions were asked: (1) what are the youth's expectations of disclosing their story to others; (2) what is the experience of youth with mental illness and disabilities in choosing to disclose their story to others?; and (3) what is important to youth about the decision to disclose or choosing to make their experiences public? Participant's experiences of disclosing were documented over four group sessions, one team meeting, one follow-up check-in, and six individual personal journals. A thematic analysis identified three primary themes: *Empowerment, Identity,* and *Meaningful Vision*. Implications of these findings are discussed. These results address an important gap in the literature on the process of disclosure for Canadian youth with mental illness using their lived experiences of sharing their stories.

Key Words: Self-disclosure, Accessibility, Mental Health, Youth, Young Adults

Acknowledgements

I would like to thank those who supported and contributed to this research, beginning with the Faculty of Education at the University of Western Ontario. I am honred to experience this learning opportunity and feel tremendiously greatful for all of the support that I received throughout this process. Dr. Susan Rodger and Melanie-Anne., thank you for all of your words of encouragement, insights, passion and most importantly, for helping me to feel empowered by my voice. This work would not have been possible without your guidance. Thank you to my family, my partner and friends for your ongoing love, support, laughter and most importantly, your patience. I would not be where I am today without all of your support and unwavering belief in my ability. Thank you to all of the participants who took part in this study, your knowlegde, experience, passion and dedication towards being agents for change is an inspiration, and it was an absolute honour to have heard your stories and work alongside all of you. Finally, I would like to thank the Youth-Serving Organization (YSO) for their support and participation in this project as well as their assistance in bringing the top ten tips of sharing your story to fruition.

Table of Contents

List of Tables

Figures

List of Appendices

Young adulthood represents a critical stage in development in which an individual is not only still forming their identity, but is also trying to figure out who they are as a member of society (e.g., Habermans & Bluck, 2000; McAdams, 1993, 2001; McLean, 2005). In our current fast-paced digital age, many youth and young adults are feeling pressured to be "real" and share intimate of details about themselves (Henderson & Gilding, 2004; Lin, Zhang, Song, & Omori, 2016). Research reveals that the majority of mental disorders can be diagnosed by the age of 25 and many youth experience the onset of their disorder during adolescence (Kutcher & Wei, 2012). As well, youth and young adults are putting themselves at considerable risk (e.g., stigma, discrimination, ridicule and alienation) through revealing such personal information (Valkenburg & Peter, 2011; Vogel & Wester, 2003). These risks can inflict significant negative social and psychological impacts on self-efficacy and identity development that can persist well into adulthood (Vogel & Wester, 2003). Thus, it is vital that these individuals receive support in helping them come to terms with their identity, including their mental health status, as they transition into adulthood. In doing so, youth may be better able to advocate for themselves, seek out the resources they need to establish and maintain good mental health, develop a strong and competent sense of self, and most importantly, figure out how and to whom they should or need to disclose their mental illness.

Within the last century, epidemiological research focusing on the mental health of children, adolescents and young adults has recognized that the mental health needs of these populations in Canada and elsewhere around the world are not being met (e.g., Burns, et al., 2004; Butler-Jones, 2011; Flett & Hewitt, 2013; Mental Health Commission of Canada, 2009). As of 2013, emerging research within the field has recognized that there is a very high prevalence of psychological disorders among children, adolescents and young adults (Flett &

Hewitt, 2013; School-Based Mental Health and Substances Abuse Consortium, 2013).

Unfortunately, relatively few youth receive appropriate psychological treatment, as many

psychological problems among younger people are simply going undetected (Flett & Hewitt,

2013; Merikangas, et al., 2011). When youths' mental illnesses are detected, individuals rarely

receive the immediate proactive or pervasive intervention treatment needed to protect against

further harm (Flett & Hewitt, 2013; Klein, Shankman, Lewinsohn, & Seeley, 2009; Malmberg,

Edborn, Wargelius, & Larsson, 2011; Merikangas, et al., 2011). Although there are children,

adolescents and young adults who meet symptom criteria for clinical disorders, there is a

substantial proportion of children, adolescents and youth who will also have psychological

symptoms, but go undiagnosed (Flett & Hewitt, 2013; Noam & Hermann, 2002).

Research analyzing subclinical mental health conditions in adolescents suggest that a

possible reason for under-diagnoses may be due to individuals presenting only some

psychological symptoms and, therefore, may not initially meet the diagnostic threshold at

present, but may eventually meet diagnostic criteria later on in their development (Flett &

Hewitt, 2013; Klein, Shankman, Lewinsohn, & Seeley, 2009; Shankman, et al., 2009).

Consequently, under-diagnosis places youth at a higher risk for developing a full blown disorder

as they progress through the school system and move on to encounter the experiences of

adulthood (Flett & Hewitt, 2013; Klein, Shankman, Lewinsohn, & Seeley, 2009; Malmberg,

Edborn, Wargelius, & Larsson, 2011; Stice, Marti, Shaw, & Jaconis, 2009).

It is important to understand the unique needs of children and youth who are struggling

with mental health problems. As of 2010, emerging research suggests that somewhere along the

developmental trajectory from childhood into adolescence and adulthood, the distinction of the

"self" from "condition" has become blurred in the public mind (Mukolo, Heflinger, & Wallston,

2010). As a result, an individual's "condition" or mental state then becomes central to the definition of their character. Thus, the stigma that was once connected with the condition becomes synonymous with the stigma towards the individual or child (Mukolo, Heflinger, & Wallston, 2010).

The epidemiological research indicates that many mental illnesses manifest in adolescence, which is a particularly vulnerable stage in the life cycle as the development of one's identity is forming (Butler-Jones, 2011; Gee, 2008; Government of Canada, 2006). Consequently, it is imperative that support be provided to help individuals transition successfully from adolescence to adulthood through developing a strong sense of self, emotional resiliency, coping skills and the ability to advocate for themselves to obtain the resources they need to establish and maintain adequate mental health (Butler-Jones, 2011; Gee, 2008; Government of Canada, 2006). Strength in these above noted areas help to equip youth and young adults with the knowledge and skills to figure out how and to whom they should or need to disclose their mental illness (Chew-Graham, Rogers, & Yassin, 2003; McCain, Mustard, & Shanker, 2007; Pescosolido, Fettes, Martin, Monahan, & McLeod, 2007).

Research shows that youth in the current digital age turn to social media platforms to aid in the process of identity development when telling their stories (e.g., Gowen, Deschaine, Gruttadara, & Markey, 2012; Morgan & Cotten, 2003; Sanders, Field, Diego, & Kaplan, 2000). Evidence of this shift was shown through a recent search (November, 2014) of Youtube.ca, with results indicating that over 8,800 youth in Canada have used social media platforms such as YouTube to self-disclose about their mental illness. However, disclosing stories about mental illness includes risks of rejection, discrimination, bullying and stigma, which can negatively impact self-efficacy and identity development (Valkenburg & Peter, 2011; Vogel & Wester,

2003). Stigma and discrimination regarding both mental illness and non-apparent disability can pose major obstacles in virtually every life domain such as finding work, gaining an education, maintaining relationships, establishing housing, medical care and accommodations, which carries significant negative social and psychological impacts that can persist well into adulthood (Valkenburg & Peter, 2011; Vogel & Wester, 2003).

The present research study seeks to provide an accessible and meaningful resource to assist in the process of disclosure for youth with mental health issues and disabilities through using their lived experiences of sharing their stories. Working in collaboration with (Youth-Serving Organization; YSO), a national mental health advocacy initiative, the current study builds upon the "In my own words: Youth with lived experiences sharing their stories of mental health" project in featuring the participation of youth in revising Corrigan, Buhholz, and Lundin's (2012) "Coming Out Proud to eliminate the stigma of mental illness" adult manual and workbook, using their lived experiences with the process of disclosure.

How is Disability and Mental Illness defined by the Government and Human Rights Groups?

According to the Public Health Agency of Canada (2006; 2013), mental illness is characterized by "…alterations in thinking, mood or behaviour—or some combination thereof—associated with significant distress and impaired functioning" (p. 2). The symptomology and typology of mental illness often varies according to a variety of factors such as the individual (e.g., age of onset of the illness and presenting issues), level of severity (mild to severe), the type of illness, environmental factors (e.g., socio-economic), and family (Public Agency of Canada, 2006).

With respect to typology, mental illness takes on many different forms, including mood

disorders, anxiety disorders, personality disorders, schizophrenia, eating disorders and addictions

such as substance dependency and gambling (Public Agency of Canada, 2006; Public Health

Agency of Canada, 2013). Additionally, mental illness can also co-occur with other disorders, as

major depression is one commonly co-occurring disorder that is affiliated with posttraumatic

stress disorder (PTSD; Cohen, Berliner, & Mannarino, 2010; Public Agency of Canada, 2006).

Despite the burden of disability that these disorders can cause an individual, the majority of

youth who require care are unable to secure much needed services (Wei, Hayden, Kutcher,

Zygmunt, & McGrath, 2013). According to the 2012 Canadian Survey on Disability (CSD), the

definition of disability includes an individual who reported being limited in their daily activity as

a result of a health problem or long-term condition, in addition to any individual who indicated

that they were limited if they were also unable to perform certain tasks without assistance

(Statistics Canada, 2013).

Prevalence of Mental Illness and Disabilities in Youth

Researchers propose that mental health problems are the leading cause of health

challenges in Canadian children and adolescents (Waddell, 2007; Waddell, McEwan, Shepherd,

Offord, & Hua, 2005). Canadian youth are found to experience the highest frequency of mental

disorders of any age group (Statistics Canada, 2002; 2003) and it is estimated that approximately

10-20% of youth are affected by mental illness, making it the single most disabling group of

disorders worldwide (Canadian Mental Health Association (CMHA), 2014).

The prevalence of youth and young adults ages 15 to 24 with disabilities within Canada is

4% (Statistics Canada, 2002), and according to the most recent data produced in 2012 by

Statistics Canada, the most prevalent types of disability reported for this group include those

related to psychological health, learning and pain (Statistics Canada, 2013). Further, research reported by Flett and Hewitt (2013) has shown that clinically important disorders (e.g., anxiety, depression, and behavioural disorders) that cause significant distress and impairment in a variety of contexts, such as within the home, at school and in the community, are estimated to occur in 14% of Canadian children at some point in time between the ages of four to seventeen years. The evidence of the prevalence of mental health disorders sends important signals regarding effective treatment.

Prevalence of Young Adults Receiving Treatment

Merikangas and colleagues (2011), found that only about one third of adolescents in the U.S. who have an identifiable mental disorder actually receive proper services for their disorder. Moreover, the research also revealed that more severe forms of psychological disorders were more likely to be addressed by psychological treatments, but even amongst those with severe mental health disorders, only half of the adolescents requiring treatment actually received it (Flett & Hewitt, 2013; Merikangas, et al., 2011). Interestingly, the results from the above study revealed that the highest levels of intervention and treatment were for more observable or behavioural forms of disorders such as adolescents with attention deficit/hyperactivity disorder (ADHD; 59.8%) and behavioural disorders (45.4%; Merikangas, et al., 2011). In contrast, fewer than one in five adolescents with a less observable form of disorder such as an eating, substance abuse or anxiety disorder received any form of treatment (Merikangas, et al., 2011). Thus, the data suggests that internalizing problems (e.g., anxiety or depression) relative to more overt behavioural problems (e.g., ADHD), have a much more diminished chance to garner therapeutic intervention (Flett & Hewitt, 2013; Merikangas, et al., 2011).

Mental Health Literacy

Research by Pinto-Foltz, Logsdon and Myers (2011), found that in conjunction with intergroup contact or social interaction with individuals from a different group, knowledge-contact is a frequently utilized approach in providing knowledge about mental health and mental health literacy. Moreover, the authors also suggested that the reduction of stigma and improving mental health literacy are two key factors in trying to enhance the healthy outcomes of adolescents and future generations of young adults seeking mental health treatment (Kutcher & Wei, 2012; Pinto-Foltz, Logsdon, & Myers, 2011).

There are four main components which encompass mental health literacy: (1) the enhanced understanding of how to obtain and maintain good mental health; (2) enhanced understanding of mental health disorders and their treatments; (3) decreased stigma and improving attitudes towards those living with a mental disorder; (4) enhanced help-seeking efficacy pertaining to mental disorders, such as knowing when to seek help; knowing how to seek help; knowing where to seek help; knowing what to expect from help; and developing competencies to assist in obtaining the most appropriate help (Jorm, 2012; Wei, Hayden, Kutcher, Zygmunt, & McGrath, 2013). All of these components are an important part of education, not only for the public regarding mental illness, but also to aid youth in engaging in help-seeking behaviours and providing support to their peers.

According to Wei and colleagues (2013), mental health literacy seeks to increase the understanding of mental health and mental disorders, facilitate help-seeking behaviours in youth, help recognize and prevent mental disorders, and reduce stigma through encompassing knowledge and skills that address the biological, psychological and social aspects of mental health and mental health care. What is different about mental health literacy programs in comparison to mental health interventions such as the application of an intervention designed to

prevent negative social behaviours, or the identification and treatment of specific mental

disorders, is that it helps to facilitate access to care among young people with mental health

problems (Wei, Hayden, Kutcher, Zygmunt, & McGrath, 2013; Wei & Kutcher, 2012; Wei,

Kutcher, & Szumilas, 2011). Importantly, mental health literacy provides knowledge that is

linked to the possibility of action to benefit one's own personal mental health or that of others

(Jorm, 2012).

Oppression and Youth Voice

Recent research by Munford and Sanders (2015), proposed that a key element in

developing a sense of agency in young adulthood is taking the time to make sense of the world.

That is, youth are taking some time to work on themselves through learning how to take control

of their circumstances, understanding their experiences and the decisions that took them to the

point where they currently are, as well as understanding how others view them (Munford &

Sanders, 2015). For some youth, their experiences have required them to suppress their voice to a

point where they felt invisible, that their opinion did not matter, which often resulted in

internalized feelings of inadequacy (Fleming, 2010; Munford & Sanders, 2015).

Similar to individuals with disabilities, youth have reported experiences of powerlessness

and their involvement in research has been limited due to ongoing debates about their level of

agency, competence and their capacity to provide an opinion due to their age (Fleming, 2010;

Oliver, 1992; Orme, 2003). Over the past two decades, few researchers have not strayed far from

the ridgid confines of empirical research to allow user-led or participant-involved research, as

user-led or participant-involved research was thought to lack clarity and definition, with

participant responses possibly provoking ambiguity and contradictions in both practice and

approaches to research (Fleming, 2010).

A key element in being able to connect with a youth and enact agency is "having a voice". For some youth this means that their opinion mattered, feeling respected, being informed and involved in the decision-making process and finally being treated as an equal (Munford & Sanders, 2015). Another key element in developing a sense of agency is establishing a meaningful relationship with the young person; this is possible by ensuring a researcher or practitioner takes the time to listen and acknowledge the youth's opinions, as well as treat them as equals in making a decision that directly impacts them (Munford & Sanders, 2015). Taken together, these arguments are persuasive in their imperative that researchers consider the dynamics of power in allowing youth to express their experiences as a means to enrich the data collected, as it is their job to ensure that the researchers' interests do not come at the risk of those of the participants, and vice versa (Fleming, 2010; Munford & Sanders, 2015).

The Process of Disclosure

As the current study focuses on the process of disclosure, it is pivotal that the various different forms of disclosure be outlined. Self-disclosure is defined as any verbal information given (e.g., private feelings, thoughts, beliefs, or attitudes) about oneself to another person (Cozby, 1973; Vogel & Wester, 2003). Essentially, disclosure is seen as an opportunity to build intimacy within personal relationships as well as develop a sense of self (Chaudoir & Fisher, 2010). Although disclosure is often associated with revealing sensitive or intimate details surrounding a specific topic to *one* individual, it should be noted that disclosure can occur in different forms and it is not limited to just one-on-one discussion: it can occur online, through self-report in a written or recorded form, or public conferences (please refer to Table 1 in the Appendix for a list of other ways to disclose; Bazarova & Choi, 2014). In relation to mental health literacy, we propose that self-disclosure is a necessary component not only as a means for

youth to obtain needed help, but also to help reduce the possibility of an individual internalizing the stigma of their symptoms.

A complex mixture of openness-closeness and our ability to manage the private and public persona typically guides the decision to self-disclose, and while it can be intrinsically rewarding to fulfill our fundamental need for belonging and social connectedness, it can also make us vulnerable by giving up personal control and privacy. As such, it would appear that decisions to self-disclose are a balancing act of conflicting needs aimed at minimizing risks and attaining strategic reward (Bazarova & Choi, 2014). To facilitate the process of disclosure, manualized guidance can provide a best practice approach in sharing their experience. However, apart from *adult* manuals (e.g., Chaudior & Fisher, 2010; Disclosure Processes Model; Corrigan & Lundin, 2012: Coming Out Proud manual), guidelines that help facilitate best practices for *youth* to utilize during the process of disclosing their stories are currently not available.

Chaudoir and Fisher (2010) discuss their Disclosure Processes Model (DPM), which "provides a framework that advances disclosure theory and identifies strategies that can assist disclosures in maximizing the likelihood that disclosure will benefit well-being" (p.236). Another model, the Ragins Model, "examines the effects of individual and environmental factors on disclosure decisions across life domains" (Ragins, 2008, p. 194). Some research suggests that this model is the most relevant for individuals with mental illness as it takes into account how the individual sees his/her identification with the stigmatized condition (e.g., "Schizophrenia is an illness that I have had versus I am a schizophrenic"; Seeman, 2013).

Traditionally, according to Ragins (1994), mental health manuals have been designed using the medical model approach, which does not consider the client as the expert. The issue with using this kind of approach in a manual is that it is quite rigid and does not allow for

flexibility, which makes it more difficult to apply the approach to a variety of patients and it can

sometimes lead to promoting or maintaining stigmatic attitudes (e.g., certain types of mental

illnesses are deemed to be treatment resistant; ibid).

Within the last decade, research has suggested that there has been a slow, but steady

movement away from using the medical model and moving towards a more holistic or wellness

model approach (Ragins, 1994). This may explain the trend toward lived experiences of

individuals with mental health disorders becoming a major aspect of reducing stigmatising

attitudes. For example, the Canadian Government, the Mental Health Commission of Canada

(MHCC; 2009) and other prominent mental health organizations (e.g., Youth-Serving

Organization; YSO) are actively trying to reduce the stigma associated with mental illness

through creating and supporting anti-stigma campaigns and calling upon youth to share their

stories in schools, professional places or work and other public venues (Mental Health

Commission of Canada, 2009). It is proposed here that the voice of youth in the context of

disclosure is not considered to be in need of support, and that youth are still not considered equal

partners in these efforts, and that youth are in need of a resource that enables them to outline the

process of safely disclosing, regardless of the platform implemented (Chaudoir & Fisher, 2010).

Manualized guidance can provide a best practice approach in sharing their experience. However,

apart from adult manuals, guidelines that help facilitate best practices for youth to utilize during

the process of disclosing their stories are currently not available. The following sections will

examine in more depth the process of disclosure for youth and outline the possible reasons as to

why individuals with and without a formal diagnosis choose to, or not to, disclose.

Reasons for choosing to disclose. The quality of life of individuals with mental illness

can significantly be undermined by stigma. Corrigan (2007), states that diagnosis can sometimes

seem like a double-edged sword as it is one of the most important parts of the system of care, but it can also intensify both "groupness" and "differentness" aspects which often govern public perceptions of people with mental illness. One reason why an individual may choose to disclose is to seek help, or try to find some answers to help them understand their current experiences. Whereas some motivations behind an individual's decision to disclose can include identity development, choosing your audience, developing your narrative, and increasing psychological well-being.

   Identity development. According to Erikson (1980), one of the major psychosocial tasks of late adolescence is identity development. The reason for the particular focus in this area is that identity development has important implications for healthy psychological development that begins in late adolescence. This life story begins to emerge in adolescence as a result of a multitude of factors such as the onset of formal operations, physiological maturity, and the demands of establishing oneself in the world through our interactions with others within a variety of environments, such as work, school and family (Grotevant, 1993; Habermans & Bluck, 2000; McAdams, 1993; 2001; McLean, 2005).

   Research on youth identity and life story theory suggests that disclosing life stories or memories helps older adolescents think about constructing their life stories in order to explain how a past event has led to, or influenced, another event or aspect of the self (Habermans & Bluck, 2000; McAdams, 1993). Thus, one reason why a youth would disclose their story is to help them figure out who they are in comparison to others (Habermans & Bluck, 2000; McAdams, 1993; McLean, 2005).

   Research by McLean (2005) suggests that identity is made up of meaning-filled experiences and also of self-defining fun experiences that induce pleasure and enjoyment.

Benefits of defining memories through self-explanation to others include allowing a sense of self to develop and strengthening the insights toward the development of self. Thus, self-explanation is an important part of identity construction. However, memories told for entertainment purposes are used to make a connection with others without the work of communicating meaning or engaging in deeper kinds of personal disclosure that may appear as riskier. Although McLean's (2005) study did provide some insight regarding the possible reasons as to why late adolescents chose to disclose their story, there were a few cautions that must be recognized when examining these results. First, the participants were asked to recall three events that were at least a year old, which subsequently leads to self-report biases as participants could have altered the stories to better suit the study. Thus, there was a threat to both internal (e.g., expectancy) and external validity (i.e., reactive effects of experimental arrangements). Second, the study contains selection bias as the participants selected for the study were primarily white, female and university psychology students, thus limiting the study's external validity.

   Choosing your audience. Although the construct of self-disclosure appears to be straight forward, the decision to self-disclose can promote a complex dilemma, especially for individuals with a concealable stigma such as mental illness or a non-apparent disability (Rüsch, Brohan, Gaddidon, Thornicroft, & Clement, 2014; Sakellari, Sourander, Kalokerinou-Anagnostopoulou, & Leino-Kilpi, 2014). The decision to self-disclose or the comfort level with disclosing can sometimes depend on the circumstances the individual is faced with and the potential results of facing either rejection through social or discriminatory means, or increased social support and acceptance (Rüsch, Brohan, Gaddidon, Thornicroft, & Clement, 2014). Thus, the decision of when and with whom to disclose to, as well as the level and type of disclosure used by individuals who have a mental illness or a non-apparent disability will often vary. Existing

research suggests that the decision to disclose or not can predominantly depend upon who the confidant is and the expected reaction of that individual (e.g., Bos, Kanner, Muris, Jasen, & Mayer, 2009; Chaudoir & Fisher, 2010). Therefore, the reaction of the confidant is one of the most important factors in predicting whether disclosure will be beneficial or not (Chaudoir & Fisher, 2010; Manne, et al., 2004).

Bronfenbrenner's bioecological model (1979) underscores the contribution of peers and influential adults on a youth's motivation to not only seeking help, but also to disclose their story (as cited in Pinto-Foltz, Logsdon, & Myers, 2011). Research by Bos, Kanner, Muris, Jansen and Mayer (2009) investigated disclosure patterns among mental health consumers and examined the relationships among disclosure, perceived stigmatization, perceived social support and self-esteem. Both mental illness and non-apparent disabilities are highly stigmatized, therefore the results suggest that selective disclosure is used to optimize social support and limit stigmatization (Bos, et al., 2009).

Individuals with mental illness and non-apparent disabilities choose to disclose to individuals with whom they trust and have a close relationship with (e.g., parents, partner, and close friend) as compared to acquaintances and colleagues because they can predict, to a certain extent, whether or not they will be supported in their disclosure (Bos, et al., 2009). In contrast, mental illness disclosure to acquaintances and colleagues was related to less supportive and stronger stigmatizing reactions. Additionally, perceived stigmatization was found to have a detrimental impact on self-esteem, especially for those who are relatively open about their mental disorder (Bos, et al., 2009).

Narratives. Young (2009), who analyzed four memoirs written by mental health consumers, found that memoirs challenge culturally dominant ideas about severe mental illness

as personal weakness and suggest that the shame surrounding this phenomenon is something that lead to isolation and marginalization. Thus, this research has argued that the act of disclosing one`s experiences with mental illness can not only help to change stigmatizing attitudes towards these individuals, but it can also provide constructive and realistic suggestions regarding how to change current support practices.

However, Corrigan and Rao (2012), explain that not every member of a stigmatized group is found to respond the same way, namely individuals who identify with having a mental illness and deem the stigma associated with it as unjust can benefit from sharing their stories. More specifically, when given the opportunity to disclose their stories of perseverance and recovery from mental illness in various forms (written expression, spoken word), many of the individuals felt as if they regained a sense of their identity from dominant, medical models of mental illness wherein the patient is not deemed as the expert, but rather a passenger in their welfare, care and recovery (Corrigan & Penn, 1999; Corrigan & Rao, 2012; Spagnolo, Murphy, & Librera, 2008; Wang, 2011; Young, 2009). Additionally, research by Watson, Corrigan, Larson, and Sells (2007), suggests that a mental illness label can also promote a sense of belonging and positive group identity as these individuals recognize that they are not alone or there are others who have silimar situations. Furthermore, it was also suggested that some individuals become empowered by their label and choose to use it as a means to overcome the discrimination associated with the label of mental illness by becoming advocates for change (Watson, Corrigan, Larson, & Sells, 2007).

Increased psychological well-being. From a psychological perspective, counselling researchers have proposed that disclosure can potentially increase positive effects, decrease distressing symptoms affiliated with self-stigma and promote better psychological adjustment.

These potential positive benefits may entice an individual with mental illness or non-discriminate

disability to want to disclose (Vogel & Wester, 2003). Additionally, individuals with mental

health issues and non-apparent disabilities may also choose to disclose to a family physician,

family or friends for a variety of reasons such as a desire to seek professional help, as a means to

help reduce risky behaviour, as a choice to cease active efforts to conceal their mental illness,

help them understand their current experiences, or to just want to be seen as normal (Bazarova &

Choi, 2014; Bos, Kanner, Muris, Jasen, & Mayer, 2009; Corrigan & Matthews, 2003; Corrigan

& Rao, 2012; Kranke, Jackson, Taylor, Anderson-Fye, & Floersh, 2013).

     Risks for youth in choosing to disclose. Choosing to disclose one's mental disorder can

pose several risks for the individual which can include facing issues with vulnerability, access to

medical treatment, stigma and discrimination. As such, it is imperative that the individual take

some time to clearly think through the various risk factors that can arise as a result of sharing

such personal information and how their decision may potentially impact their future.

     Issues of vulnerability in the process of disclosure. Research by Seeman (2013),

suggests that the reluctance of disclosure, especially in the area of mental illness, is often based

on the fear that an individual's identity will be inaccurately equated with their diagnosis and the

negative effect that an individual's accomplishments and uniqueness will be compromised or

dismissed by the mere fact that they are an identifiable member of a stigmatized social group.

Possible risks of self-disclosure or choosing to disclose include rejection, discrimination and

perceived stigma. Apart from discrimination and perceived stigma, the possibility of social

rejection is one of the most common reasons listed for individuals with mental illness not to

disclose or seek out individuals to disclose (Manne, et al., 2004). Thus, revealing any personal or

intimate information about oneself could be viewed as a negative action that promotes gossip,

disapproval or social ostracism and is, therefore, avoided at all costs (Manne, et al., 2004).

Disguised or hidden psychological distress is much more prevalent among younger

people than we realize. There are a multitude of factors that can contribute to a young person's

distress (Flett & Hewitt, 2013; Miller & Jome, 2010). For instance, the distress can be a result of

the mounting exposure to life stressors which include the pressures to be perfect as well as life

conditions that make it difficult to maintain a positive possible self, as well as concerns about

being stigmatized. Social media is another potential factor contributing to a young person's

hidden psychological distress as the increasing use of social media enables these adolescents to

maintain superficial attachments to others, thus allowing them to keep their true feelings

unknown or hidden (Flett & Hewitt, 2013; Miller & Jome, 2010). Valkenburg and Peter (2011),

state that young people who are determined to hide their distress may never be detected as long

as they remain relatively detached from others online and they have the prerequisite social skills

to present an idealized image. It is also highly possible that these self-presenters may never

receive treatment as they may be superb at manipulating the clinical assessment process should

they be detected (Valkenburg & Peter, 2011; Vogel & Wester, 2003).

Issues of access to mental health treatment. Apart from stigma, access is another issue

that places barriers on youth regardless of a formal diagnosis, as some youth may recognize their

own symptoms as a direct result of their subjective experience. The issue then is that some youth

may recognize their symptoms, but may not know how to access mental health services. These

access barriers can include being raised in a culture that is less open about mental health issues

and where the idea of saving face and other cultural values significantly reduce the likelihood of

a youth seeking potentially beneficial treatment for their psychological problems (Fang, Pieterse,

Friedlander, & Cao, 2011; Flett & Hewitt, 2013).

Furthermore, being diagnosed or seeking treatment places individuals in a vulnerable

position due to the fact that much of mental health diagnosis and treatment relies on direct

communication rather than objective tests. As well, language barriers can also pose a

problematic barrier for new immigrants (Ganasen, et al., 2008; Sentell, Shumway, & Snowden,

2007). As such, language and citizenship status (e.g., refugee or new citizen) may also influence

the level of access a youth has to mental health services. Given that these individuals may

already feel vulnerable being in unfamiliar surroundings and not being able to speak the

language, it is quite possible that new immigrants may be less likely to seek out, or know how to

access mental health services (Ganasen, et al., 2008; Sentell, Shumway, & Snowden, 2007). In

addition to cultural influences, privilege also plays an influential role with respect to access, as

research suggests that almost 80% of youth involved in child welfare agencies have been found

to have developmental delays, emotional or behavioural disorders, or other indications of

needing mental health intervention (Burns, et al., 2004). In contrast, roughly one fifth of youth in

the general U.S. population, are diagnosed with a mental disorder (Burns, et al., 2004).

   Stigma. In the area of mental health, stigma presents a significant barrier to access mental

health services (Mukolo, Heflinger, & Wallston, 2010). Social contempt displayed by the

general public is often a result of stigma and this stigma can rob individuals labeled as mentally

ill from a variety of opportunities such as housing, work and access to clinical services and other

life opportunities commonly enjoyed by adults who do not have a label (Corrigan, 2007). In an

effort to avoid being labelled and, therefore stigmatized, some youth may not only avoid

pursuing beneficial clinical services and treatment, but may also put in an extraneous amount of effort to conceal their illness from others (Corrigan, 2007).

A disguised or hidden distress condition is particularly evident among younger individuals due to their elevated sense of self-consciousness and their ability to reflect upon and distinguish individual differences, thus, contributing to their unwillingness to disclose distress (Flett & Hewitt, 2013; Miller & Jome, 2010). For instance, research by Drauker (2005), found that adolescent girls with an eating disorder appear to be highly focused on creating a positive presentation of themselves (e.g., hiding evidence of negative emotions) and emphasizing positive emotional displays. Flett and Hewitt (2013) propose that some younger individuals who are distressed appear determined to conceal their flaws and mistakes including their psychotic or psychological symptoms, no matter the cost. Personality features such as elevated levels of trait self-concealment and perfectionistic self-presentation, which is often found in these individuals, make it highly unlikely that these individuals will self-disclose, even if they experience severe psychological distress or pain (Miller & Jome, 2010).

Regardless of specific psychiatric disorders, mental illness has been found to be one of the most stigmatized conditions in our society (Corrigan & Lundin, 2000; Spagnolo, Murphy, & Librera, 2008). This stigmatization can significantly reduce the opportunities (job interviews, housing) and rights of individuals suffering from mental illness to participate fully in society. As well, it can impede an individual`s recovery from mental illness due to limited access to treatment and decrease the likelihood of seeking support (Rüsch, Brohan, Gaddidon, Thornicroft, & Clement, 2014; Stuart, 2005).

At the structural and instructional level, stigma has impacted mental health programs, treatments, policies, services and supports in such a way that they no longer meet the needs of

individuals struggling with mental illness (Mental Health Commission of Canada, 2009). At an

intimate level, stigma can also become internalized by individuals who have personally

experienced mental illness, leading to internalized feelings of shame, guilt, inferiority, wish for

secrecy as well as increased beliefs that public stereotypes are truth (e.g., a person with a mental

disorder is incompetent; Stuart, 2005; Vogel & Wester, 2003). Negative attitudes or stigmatizing

beliefs towards mental health can also inhibit individuals who are at risk of a psychiatric disorder

from using potentially beneficial mental health services (Corrigan, 2007; Kessler, et al., 2001).

Another important factor to consider in self-stigmatization is perceived legitimacy of

public stigma. That is, the variance in the perceived legitimacy of public stigma can influence the

tendency one has to internalize public stigma and decrease self-esteem/efficacy in adult mental

health consumers (Watson A. , Corrigan, Larson, & Sells, 2007). More specifically, findings

from Watson and colleagues (2007) found that adults who view public stigma as legitimate are

often at a higher risk of internalizing public stigma and experiencing a significant decrease in

their self-esteem, self-efficacy and seeking behaviours for mental health services. However, the

findings also found that adults who view public stigma as illegitimate predict higher involvement

in anti-stigma initiatives and seeking professional mental health services (Mukolo, Heflinger, &

Wallston, 2010; Watson, Corrigan, Larson, & Sells, 2007).

Corrigan (2007) proposed that the stigma process occurs in relation to four cognitive

structures: cues, stereotypes, prejudice and discrimination. This model parallels a cognitive

behavioural model of action by specifying a signal (cues that signal subsequent prejudice and

discrimination), cognitive mediator and behavioural result. Goffman (1963), suggested that some

stigmas are readily apparent and are based upon physical signals or signs such as body size (cue

for obesity) or skin colour (cue for ethnicity), while other stigmas are not readily apparent and

are relatively hidden. For example, it is often quite difficult to tell who, among a group of

people, would be placed into a stigmatized group based on a non-discriminant disability or

mental illness, their sexuality, religious beliefs, educational background, or mental status. Since

there are no physical cues that provide the public with an obvious reason to place an individual

into a specific stigmatized group, hidden stigmas are signaled by a label or association (Corrigan,

2007; Goffman, 1963). These labels can be self-promoted, given by others, or can be ascertained

based on association or assumption such as seeing an individual leaving a psychiatric wing or

walking out of a known psychiatric clinic and assuming that they are mentally ill (Corrigan,

2007). Researchers propose that stereotypes are a form of learned categorization (knowledge

structures) by most members of a cued social group. It should be noted that although we have

this knowledge base on a set of stereotypes, it does not imply we agree with them, thus new

knowledge structures are formed (Chew-Graham, Rogers, & Yassin, 2003; Corrigan, 2007;

Corrigan & Rao, 2012; Corrigan, Watson, & Barr, 2006).

  Discrimintation. The risk of being discriminated against in housing, employment and

other opportunites is also another cost of disclosure. Research suggests that anticipated

discrimination by others, such as social rejection, appears to have a greater impact on an

individual's comfort level with disclosure. Individuals may have experienced discrimination in

the past due to their disclosure, and thus feel that they may not have sufficient resources to cope

with the rejection (Rüsch, Brohan, Gaddidon, Thornicroft, & Clement, 2014; Stuart, 2005). Self-

stigma is the idea that the individual with the mental illness or non-apparant disability agree with

public stereotypes and view them as truth. Thus, they expect to become devalued and stigmatized

against and use internalized feelings of shame, guilt and inferroriy to exclude or ailinate

themselves as a form of self-protection (Rüsch, Brohan, Gaddidon, Thornicroft, & Clement, 2014; Stuart, 2005).

Following this brief literature review, it is evident that understanding youth mental illness, the promotion of competencies to develop and maintain well-being and understanding these in the developmental context of self-identity are all important concepts. The research presented outlines a project that was designed to draw these concepts together within the context of a process designed to support youth and young adults as they make the decision about whether or not to disclose their personal experiences of mental health disorder to others and the factors that influence both their cognitions and actions.

My personal reasons for conducting this research are twofold. For the past 10 years, I have personal and professional experience in working alongside individuals with disabilities, exceptionalities and mental health issues. Through this experience, I have come to understand the vital role that using lived experience can play in reducing stigma. Moreover, I have also had many opportunities to highlight the importance of providing equal accessibility within all life domains (e.g., education, work force, recreation activities, public services, and so on) as well as on a political platform through my work with the Canadian Union of Postal Workers. As a consumer and mental health professional in training, I have also come to recognize that the decision to disclose one's story can sometimes be seen as a double edged sword as mental illness and disabilities are often associated with stereotypes and stigma. To help provide some guidance on the decision to disclose and reduce the stigma associated with the decision, I wanted to develop a resource that would not only be relatable and meaningful to the process of disclosure, but also highlight the importance of using lived experiences.

Purpose of the Study

My goal for this project was to address an important gap in the literature on youth lived experiences with mental health issues and the process of disclosure. The research presented here outlines a project that was designed to provide an accessible and meaningful resource regarding the process of disclosure for youth with mental health issues and disabilities, using youth's lived experiences of sharing their stories. My research questions asked:

(1) What are the youth's expectations of disclosing their story to others?

(2) What is the experience of youth with mental illness and disabilities in choosing to disclose their story to others?

(3) What is important to the youth about the decision to disclose or choosing to make their experiences public?

Working in collaboration with (Youth-Serving Organization), a national mental health advocacy initiative, I assisted with expanding the "In my own words: Youth with lived experiences sharing their stories of mental health" project in revising Buchholz and Corrigan (2012) "Coming out proud to eliminate the stigma of mental illness: Workbook" and Corrigan and Landin's (2012) "Coming Out Proud to Eliminate the Stigma of Mental Illness: <u>Adult</u> manual", a program providing instructions and exercises on adult practices for self-disclosure. This work effort assisted in filling an important gap in the literature by developing a framework for studying, documenting and supporting youth with lived experience as they participated in the disclosure process.

Method

The study received approval from a university research ethics board (see Appendix A). The present study was phenomenological. Through a qualitative, descriptive approach, the current study was designed to gain an understanding of how the process by which youth in the age range of 18 – 25 years with lived experience create, share and reflect on their own experiences with mental health and cross-disabilities and how this method could be applied to Corrigan, Buchholz, & Landin's (2012) "Coming Out Proud" adult workbook and manual. In order to develop an understanding of the youth's process of disclosure, the weekly group meetings and follow-up check-in were documented and audio-taped. A thematic analysis was used to examine the youth's descriptions of their lived experiences and how these could be applied to the revision of the current workbook and manual, which was originally designed for adults.

Participants

The convenience sample of five youth participants recruited for the study (4 females, 1 male, M_{age} =22 years, $SD = 2.33$, age range:19-25 years) were over the age of 18, had self-identified as having lived experiences of mental illness , were currently involved with (Youth-serving organization; YSO), a local non-profit organization that engages and works alongside youth and young adults to support their mental health) and previously participated in the "In my own words" project conducted in the summer of 2014. Although participants were not asked to provide specific demographic information on their ethnicity, nor the type of mental illness they self-identified with, the majority of the participants were Caucasian and Middle Eastern (first generation Canadian). Moreover, the types of mental illnesses participants self-identified as having included one or more of the following: dysthymia, bipolar disorder, anxiety (social and

generalized), and depression. In addition to having one or more mental illness (e.g., Bipolar

disorder and Anxiety), some participants also expressed having developmental or intellectual

disabilities such as Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity

Disorder (ADHD) that coincided with their mental illness.

The individuals participated in a five-week focus group that discussed their experiences

with disclosing their story using Corrigan and Landin's (2012) "Coming Out Proud to Eliminate

the Stigma of Mental Illness" adult manual, Buchholz and Corrigan (2012) "Coming Out Proud

to Eliminate the Stigma of Mental Illness" workbook. Given the youths' ages and their

confidence level as being self-identified as having lived experience with mental illness, they

were deemed to have rich insights into developing a manual that a youth target audience would

need to enrich their ability to examine the process of disclosure.

In addition to the youth participants, two adult employees of (Youth-Serving

Organization) (2 females) asked to participate in the focus group. Their role was to help facilitate

the sessions, provide their feedback based on their experiences in working with self-identified

youth with mental illness and help with the recruitment process. All participants within this

convenience sample and the employees used English as their first language. Including the criteria

listed previously, any participants under 18 years of age were not invited to participate in the

study. In addition, it should be noted that information regarding level of education, socio-

economic, generational, or immigrant status and sexual orientation was not collected on any of

the participants as it was not pertinent to the current study.

Youth participants involved in the research study were provided nominal compensation

for their participation in each of the five weekly meetings for the research project, including

$20.00 per weekly session (total of $100) and transportation compensation.

Recruitment. Two employees of (Youth-Serving Organization) assisted with the recruitment process by identifying potential participants who fit the inclusion criteria, sending a letter of information (see Appendix B) and a consent form (see Appendix C) to these potential participants, and inviting interested participants to attend the first session at (Youth-Serving Organization), where the details of the study were provided. At the end of the information session, invitees were asked to sign the letter of consent if they so chose. All participants who signed the consent form were asked to meet weekly for four additional weeks at (Youth-Serving Organization) to participate in the study. All those who met the inclusion criteria and were interested in participating were invited to participate. As there were fewer than 10 participants who volunteered, a second focus group was not needed.

Materials and Procedure

In order to develop an understanding of the process of disclosure, the youth were asked to review the costs and benefits of sharing their story, investigate different ways to tell their story and evaluate their experience formulating their stories. Once they had reviewed their experience, youth participants were asked to assist in a revision and re-write of Corrigan, Buchholz, & Landin's (2012) <u>adult </u>manual and workbook to make it more appealing and applicable to their experience as youth. To assess how the participants developed their stories about their experiences with mental health and the process of disclosure, Corrigan and Landin's (2012) "Coming Out Proud to Eliminate the Stigma of Mental Illness" adult manual and Buchholz and Corrigan (2012) workbook—for program facilitators and participants, a detailed outline for each weekly meeting (five sessions in total) created by the researcher (see Appendix D), a modified detailed outline for the fifth weekly meeting created by the participants and (Youth-serving organization) staff (see Appendix E), follow-up check-in questions (see Appendix F), and journal

with reflective questions (see Appendix G) were used. It should be noted that at the request of

our project partners (YSO), the objective of the fourth meeting was modified to discuss some of

their concerns regarding the manual and workbook. To ensure that the process of the

participant's disclosure was documented, the researcher facilitated the five weekly group

meetings.

The manual provided detailed, step-by-step instructions regarding how to facilitate the

program, while the workbook provided the lessons and activities for the group participants to

complete. To help facilitate the weekly meetings and promote discussion, a detailed outline of

the weekly activities was developed by the researcher (Appendix D) and a revised outline was

created by the youth and (YSO) staff for the fifth session only (Appendix E). The original

detailed outline incorporated the youth's feedback from the "In my own words" project (i.e.,

likes, dislikes and suggestions for improvements), session goals, activities to promote discussion

and references to specific portions of the workbook to confirm the youth's suggestions for

improvement. The revised outline for the fifth session consisted of goals, icebreakers, interactive

activities to promote discussion and creation of a new resource and a wrap-up. The follow-up

check-in questions (see Appendix F) were developed following a review of existing literature on

self-disclosure and youth engagement. The reflective questions in the journals were provided to

obtain data rich feedback from the youth on each session (see Appendix G).

Materials. Prior to the first session, all participants and (Youth-Serving Organization)

facilitators were provided with a digital copy letter of information (please refer to Appendix B), a

consent form (please refer to Appendix C) which outlined the purpose of the study and any risks

associated with participating in the study, as well as a detailed outline of the session activities. In

the first session, all participants were provided with a hard copy of the letter of information and

consent form. Once the consent form was signed, participants were then provided with the

following materials that were supposed to be used throughout the five sessions: a detailed outline

of all the sessions included session goals, activities, discussion questions, and references to

specific portions of the workbook (refer to Appendix D for a detailed description of all five the

session outlines); a binder from the first part of the study which included the Bucholz and

Corrigan (2012) "Coming Out Proud to Eliminate the Stigma of Mental Illness" workbook; a

notebook—for recording the youth's thoughts and assist with brainstorming; sticky notes—to

indicate sections of the workbook that needed improvement; writing utensils (e.g., pens, markers,

highlighters, pencils); a name tag and a journal for reflection at the end of each session. At the

end of every session, the participants were asked to reflect on what was discussed in the current

session using their journals and the four questions provided in their journals. Please refer to

(Appendix G) for a detailed list of the questions provided in the reflection journals. To provide

transparency, the researcher reflected on her experience in a journal after each session. Each

session was audio-taped using a digital recorder to ensure the accuracy of discussion throughout

each session, as well as the accuracy of the transcript of each that followed.

Procedure.

Purpose of the weekly sessions. The purpose of the weekly sessions was to develop a

detailed understanding of youth's process of disclosure through the revision and reflection upon

the participants' experiences during the first phase of the study. This revision investigated the

different ways in which participants told, formulated and evaluated their experience of sharing

their stories through re-writing Corrigan, Buchholz, & Landin's (2012) "Coming Out Proud to

Eliminate the Stigma of Mental Illness" adult manual and workbook. More specifically, the

participants were encouraged to discuss their likes, dislikes and suggestions regarding how to

improve the adult manual and workbook in order to develop a new resource that would be

relatable to youth. The following section provides a framework of the five sessions used to

investigate this process.

   Location and parameters of the sessions. Each week, four of the five youth participants,

the researcher and the co-facilitators (YSO staff) met at the (Youth-Serving Organization) space

in Southwestern Ontario. However, one participant was unable to physically commute to the

(Youth-Serving Organization) space for each meeting which resulted in her using one of the

following telecommunications: Skype, Google hangout, or telephone. Each session was to be

three hours in length for five consecutive weeks for a total of 15 hours, however due to a change

to the agenda for the fifth session, the final session was 6 hours in length.

   Session Outline.

   First session. In the first session, the goal was to establish rapport between the

participants, facilitators and myself, to develop group cohesiveness and familiarity with each

other as well as to discuss the purpose of the study. To accomplish these goals, the first activity

of the session provided time for introductions, using an ice breaker exercise as well as discussing

the purpose of the study. Following the icebreaker exercise, the researcher discussed the

importance of self-care to ensure that youth were supported in sharing their stories. Should the

participant (s) feel distressed either during or after the sessions, the researcher provided them

with appropriate supports which included, but were not limited to, contact information for

support and crisis services that the youth had access to within the (local region) as well as

assisting the participants in connecting with such services should they feel a need at any point

during and after the sessions.

After the participants were provided with self-care options, they were asked to review the detailed outline of the sessions created by the researcher and contribute to establishing the goals of the current session. Once the goals were established and agreed upon, the participants reviewed the suggestions that they provided on the workbook and manual during the first phase of the project ("In my own words") using the notes they took in their binders. The participants were then encouraged to reflect upon their experience with using the workbook in their decision to disclose. After reflecting upon their experience, they were encouraged to participate in a group discussion which focused on their expectations and reservations they had about disclosing their story both before and after using the workbook, as well as examining what aspects of the book worked for them in their decision to disclose. At the end of the session, the participants were asked to write an entry in their journal using the journal questions as a guide for their entry (refer to Appendix F for the questions asked).

Second session. The goal of the session was to work on improving Lesson One of the workbook "Considering the Pros and Cons of Disclosing" (Buchholz & Corrigan, 2012), which explored the diversity of how individuals who have experienced mental illness viewed themselves and the detailed reasons why individuals choose to disclose their status as a person who has experienced mental illness. It also reinforced the fact that everyone has the right not to disclose if they so choose (Buchholz & Corrigan, 2012). In this session, participants:

1. Engaged in a grounding exercise (i.e., beach visualization meditation) to help them relax and clear their minds prior to starting the session activities.
2. With the researcher, reviewed what was discussed in the previous session and developed goals for the current session.

3. Reflected upon their experience with this first lesson and worked on creating stories or using personal experiences to make it more relatable to youth audiences.

4. Discussed the reasons why they thought the manual should be re-written for youth and engaged in the first interactive activity, which explored how they define themselves and their experiences with mental illness.

5. Reflection and participation in a lively discussion on the experience so far

6. Drew upon these experiences to provide suggestions regarding how to improve the workbook to make it more applicable to youth.

7. Participants were asked to reflect in their journals about their experience in participating in the second session.

Third Session. The third session also focused upon improving Lesson Two of the workbook "There are Different Ways to Disclose" (Buchholz & Corrigan, 2012) to make it more relatable to the youth audience. Lesson two discussed the costs and benefits of five different ways to disclose about mental illness. The activities were quite similar to those listed in Session Two, and they closed with discussing their experience in disclosing their story to others, and how to implement the improvements they had identified earlier and provided suggestions for change from the previous phase and the workbook activities. Finally, the participants were asked to reflect in their journals.

Fourth session. Prior to the fourth session, the objective of the session was modified from the original detailed outline at the request of our project partners (Youth-Serving Organization) to discuss some concerns that were raised regarding the manual and workbook. This modification required all stakeholders to be present at the meeting to discuss some concerns

regarding the manual and workbook. It should be noted that the change in the objective for this

session did not include an outline but rather, it was designed to be an open discussion between all

of the stakeholders involved in the current study (i.e., YSO staff members, five youth

participants, the researcher and her supervisor). Following this meeting, the outline for the fifth

session was modified from its original design as the participants organized and facilitated it.

Please refer to Appendix C for a detailed outline of the original lesson plan for the fourth session.

At the end of the meeting, all parties agreed that the participants, the (YS O) staff, and the

researcher would collaboratively take over the planning and facilitation of the final session,

which included the creation of a detailed outline of the final session as well as the materials

needed for said session.

   Fifth session. In the fifth session, the goal was to create a resource for youth who are

considering sharing their experiences with mental illness in a public manner. To accomplish this,

the participants were asked to reflect upon their own past experiences, expertise, suggestions and

considerations they collected while reviewing Corrigan and Lundin (2012) "Coming Out Proud

to Eliminate the Stigma of Mental Illness" adult manual, and Buchholz and Corrigan (2012)

"Coming Out Proud to Eliminate the Stigma of Mental Illness" workbook. The process of the

resource creation was documented as a means to guide future research that focuses upon youth

mental health and involves youth as research partners.

   At the beginning of the session, the group engaged in a check-in activity which discussed

the day's goals and an icebreaker activity. Next, the group identified important considerations for

the resource and divided them up into themes to assess what content will be included as well as

how it should be presented. The second activity, weighed out the costs and benefits of different

forms of presenting the information (i.e., text, video, infographic) as well as promoted a

discussion to determine how to convey the information to reach the target audience using a sticky note wall. After breaking for lunch, the third activity reviewed the sticky note wall containing the content and themes in order to discuss and bring together the content for the decided upon resource in a manner that utilized the youth adult partnership and combining participants experience and expertise with clinical knowledge. Following another short break, the fourth activity was designed to promote the development of what the final resource should look like as well as finalize what the group was able to create given the time constraints. In the final activity, the group participated in a wrap-up and follow-up check-in, which included an opportunity to present feedback on the day, the project as a whole, as well as provide their reflections (written or verbal format) regarding their own personal experiences during the story development process. Please refer to Appendix F for a copy of follow-up check-in questions that were asked.

All verbal follow-up check-ins were audio-recorded, but it was not mandatory for participants to agree to such recordings in order to participate. That is, if a participant did not wish to be audio-recorded in a group session, the researcher (who transcribed the recordings) would not transcribe anything they said. As an alternative to providing oral responses, participants were given the questions in written form and asked to respond in writing. Once the participant had completed their written responses, they were asked to share these responses with the researcher with the same assurances as those who were being recorded (they could refuse to answer any or all of the questions). All permitted audio recordings were transcribed, measures were scored and data analysis was undertaken.

Data collection. Each meeting was approximately three hours for four weeks, with the exception of the fifth session which was extended to six hours. Participants were provided with

bus and train tickets to assist with transportation to and from the research study site. Each

participant received $20.00, two bus tickets or two train tickets at the beginning of each of the

five sessions, so that their participation is not contingent upon staying or participating during the

entire session. A digital recorder to capture the participants' verbal responses during each

session and the participants' written reflections of each session were utilized with their

permission at the end of the fifth session. In addition to the participants' journal reflections, I

also completed a journal at the end of each session. The follow-up check-in was used to provide

participants the opportunity to reflect on their own experiences of sharing their story. Each

session was audio recorded as permitted to ensure the quality of the data collected.

Analysis. To analyse the data, Creswell's (2009) six steps were used. First, the data was

organized and prepared for analysis through manual transcription of the audio data, written

responses of participants' journal entries and the information gathered from the follow-up check-

in during the fifth session. Second, all of the transcriptions from each session were read in order

to gain a general sense of the information provided in each session and reflected on the overall

meaning of the data. Third, a descriptive and thematic analysis was conducted based on the

narrative content to search for common themes that may arise throughout each session. Fourth, a

description of the (Youth-Serving Organization) space and focus group was generated to identify

any common themes from the participants' lived experience and participation in this project to

gain a better understanding in relation to how these themes could be applied to the manual. Fifth,

the outcome data was represented within a research report. Finally, the larger meaning of the

data was interpreted to provide a succinct analysis in the results section of the current research

study.

Results

Field Notes and Observations

Using my field notes, I reflected upon the potential impact that my beliefs, values and biases may have had on the collection and outcome of the data. More specifically, three examples of my potential influence on the outcome of the data were identified: *group dynamic, objective of the sessions,* and *language used*. Additionally, as mentioned previously in the methods section, one participant telecommuted to the sessions, given that the process was not the same for all participants it is possible that the outcome of the data may have been impacted as a result. These potential influences and my reflections on the data collection process will be shared within the discussion section.

Thematic Analysis

Based on the data analysis, the following three broad themes (each with two to four subthemes) were identified: *empowerment, identity,* and *meaningful vision*. For a qualitative representation of the frequency in which each broad theme and corresponding subtheme were identified by the participants please refer to Table 2.

Table 2. *Total frequency of themes and subthemes for youth participant's in sessions 1-4*

Themes	Variant (1person)	Common (2-3 persons)	Typical (4-5 persons)
Theme 1 – Empowerment			
A. Communication (sharing your story)		X	
B. Education		X	
C. Agency / Communion		X	
D. Self-Care/ Preparation			X
Theme 2 – Identity			
A. Language – Representation			X
B. Authenticity – Need to connect/disconnect		X	
Theme 3 – Meaningful Vision			
A. Product – Final product expectations and concerns			X
B. Process – Staying on task and brainstorming		X	

Empowerment, including the subthemes of *communication, education, agency/communion,* and *self-care/preparation*, encompassed an overview of the participants' efforts in communicating, educating and advocating their knowledge, expertise and experience with mental illness to others and the need to provide self-care and preparation considerations for sharing their experience to others. The second theme, *identity* and its subthemes of *language* and *authenticity*, highlighted how the participants and the public tend to view individuals with mental illness, as well as the importance of authenticity in representing individuals with mental illness. The final theme, *meaningful vision* and its subthemes of *product* 1and *process*, gave a voice to the participants in their vision, expectation, suggestion (ideas), concerns, and focus towards the development and completion of the customized youth workbook and manual. It is important to note that the identified categories are not mutually exclusive. Given the dynamic nature of each participant's unique experiences with mental illness and sharing said experience, many factors overlap and impact one another. For a visual representation of the major themes and their corresponding subsequent themes please refer to Figure 1 below. For a representation of the frequency of the major themes and their corresponding subthemes please refer to Table 2.

Empowerment	Education
	Communication
	Agency/ Communion
	Self-Care/ Preparation

| Identity | Language - Representation |
| | Authenticity - Need to connect/disconnect |

| Meaningful Vision | Product |
| | Process |
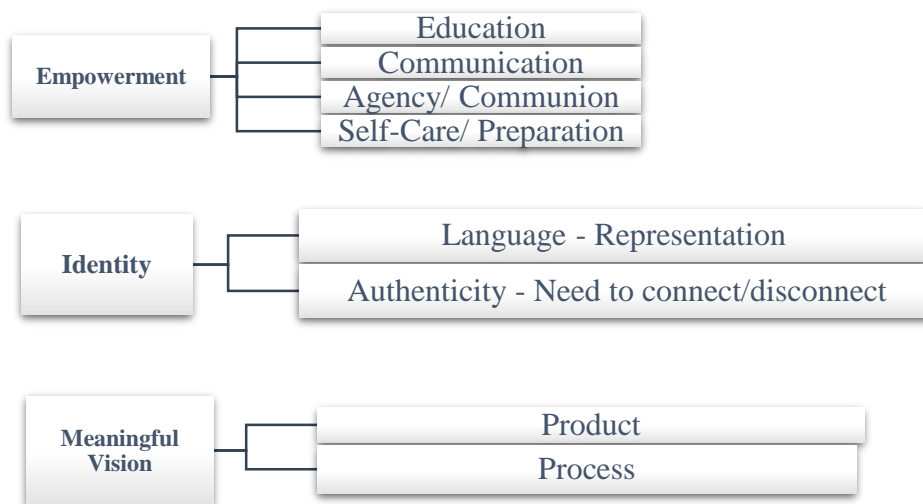
Figure 1. Major themes and subthemes for the thematic analysis.
Rectangles on the left represent the major themes and the rectangles on the right represent the corresponding subthemes. The lines represent the relationship between the themes.

Empowerment

The first theme, *empowerment*, provided an overview of the participants' efforts in using their voice to communicate, educate and advocate, their knowledge, expertise and experience with mental illness, as well as disclosing their story to others. In discussing their experiences with using Buchholz and Corrigan (2012) adult workbook and Corrigan and Lundin (2012) adult manual with the intent to share their story upon completion, the participants highlighted *communication, education,* and *agency/communion* to be important influential factors in having an increased sense of self in relation to one's experience with mental illness. In addition, while describing their experiences, participants repeatedly spoke to the important role that *self-care/preparation* played on their level of readiness to share their story.

The participants readily recognized that an increased sense of self-awareness in relation to one's experience with mental illness, as defined by the participants, related to seeking internal validation about their experiences. This included the ability to defend their experiences through the use of communication, education and agency. One participant discussed how she increased her sense of self-awareness by reflecting on her personal motivation or goal for sharing her story:

…the goal shouldn't be some kind of external validation it should be… I feel

comfortable with my story and my experience… it shouldn't be… some kind of steps

for the outside world, it should just be… I've told who I've needed to tell or doing

what I need to do with it… [Participant 5]

In addition to the benefits of understanding the motivations behind an individual sharing their story, another participant described the necessity of an increased sense of self-awareness as having knowledge about their experience with mental illness. This participant described her experience of increasing her self-awareness as the ability to draw upon the knowledge she obtained from volunteering with a national youth organization and other personal research as a means to defend against stigmatizing comments:

…not everybody who has depression is lazy…knowledge is empowering…being with a (national youth organization) made me feel so much better when I was dealing with my high school stuff with my teachers saying "oh you're lazy not attending classes" …coming here to volunteer and learning that I am not alone on this…I wouldn't have been able to actually defend myself on that matter (what she was experiencing) if I didn't have access to that information (referring to information on depression)…so to have information on that I think would really be useful for people to be able to feel a bit more empowered to be assertive. [Participant 3]

Communication. In order to comprehend the needs of youths with mental illness and their level of readiness to share their story with others, it was important to have a contextual understanding of the participants' experiences and expertise as self-identified youth with mental illness in their decision to share their story. This subtheme includes the emphasis of choice in sharing one's story and in developing the guide; the type of language/ tone used to relate to the audience in developing the guide and sharing one's story; and finally the participants sharing their experience with readiness to share.

Participants readily recognized the necessity of developing a guide that was meaningful, accessible and relatable to youth with mental health issues. One of the most frequently expressed

challenges that the participants raised in using and revising Buchholz and Corrigan (2012) adult

workbook and Corrigan and Lundin (2012) adult manual was that they felt it was too ridgid—

leaving little room for the reader to freely choose how they want to express their story to others.

As well, they found it to be un-relatable to their experiences as youth with mental health

concerns. As such, the participants repeatedly commented on the importance of providing a

choice to the reader regarding when they should share their story and how much of their story

should be shared. One participant shared:

> I think for me what was important was knowing that you don't have to share
>
> everything. It is not like an all or nothing. You are gunna sit down with somebody
>
> and tell them, in my case, 25 years of life. You can do a full disclosure or you can
>
> just do a Coles notes version, whatever is relevant in the conversation of disclosure.
> [Participant 5]

To ensure that the reader (youth with mental illness) felt comfortable with their decision

to share their story, the participants spent a great deal of time focusing on the type of language

and tone they wanted to use in their guide to emphasize the power of choice in the decision to

share their story. One participant described the necessity of choice when contemplating a

decision to share their story:

> I think the best way to at least try to communicate, that is to say... it is your choice.
>
> We can list some things that maybe will show that you are ready or aren't ready, but
>
> at the end of the day, this choice is completely up to you because I think…people
>
> hold themselves to that (referring to the decision) and they think that they are set in
>
> stone… [Participant 5]

Education.   There are multiple factors that can impact one's increased sense of self. For the participants, *educating* self and others about mental illness and their experience with mental illness was very important in terms of internal validation. This subtheme included participant experiences with educating themselves and others to combat stigma, public stereotypes to validate their own experience with mental illness.

To educate self, the participants discussed the methods they used to find support and protect themselves from public stereotypes, self-stigma and public stigma. Although not all participants shared their experiences, they did highlight the importance of self-education in terms of internal validation. Some participants expressed that they conducted personal research on their experience with mental illness, while others shared their experience with seeking out support from mental health professionals and organizations that work with individuals with mental health issues. Both methods of self-education were used as a means to better understand their own experience with mental health. One participant shared their experience:

> …I can't speak for other people's experience, but for me it was…when I volunteered more and more at (national youth organization) …It became easier for me to just talk about it (referring to her experience) … I'm just a person who is…who likes to always educate myself and I'm a student forever and not by institution but by…life …and I … I'm also a person who identifies as person who goes through experiences with … mental illness … and I like to always create a safe space for everybody…
> [Participant 3]

To the participants, the term educating others meant connecting with both the readers and the individual (s) with whom the youth would share their story, including friends, family, online community (e.g., Facebook, twitter, YouTube, or other social media sites) as well as educating

the general public which could include acquaintances – meeting people for the first time or

public speaking – in a conference as a guest speaker, or delivering a presentation. More

specifically, when the participants discussed their own personal experiences of educating others

about mental illness, they used terms such as "*calling-in*" (to speak privately with someone) vs.

"*calling-out*" (to correct someone publically) and *teachable moments*. The participants saw these

terms as a form of empowerment because they highlighted their ability to choose when to

educate others about their knowledge and experience with mental illness. One participant shared:

> …You're trying to…take away that stigma so…it should be something that is more
>
> …between you and that person *calling–in* is something that gives you more
>
> empowerment because…then you can do it privately and it can be your own thing
>
> …It's an idea that…I don't have to…compromise myself, I don't have to sacrifice
>
> myself by putting myself in a weird position about correcting something. I can just
>
> say, "hey, come over here" … It's more of an empower thing … Once I had
>
> somebody joke about how bipolar the weather was and I just quietly said "well…it's
>
> not bipolar but it's…very… iffy" and then later on…I just went to talk to them in
>
> private… [Participant 3]

In addition to "calling- in" or "calling-out" people as a means to educate them, the

participants also highlighted their motivation for sharing one's story as a major contributor

towards the decision to educate themselves and others. One participant stated that the

motivation for sharing her story with others was the idea of educating others as a means of

internal self-fulfillment. She shared,

> … I think it would be easier to talk about fulfilling yourself internally, as well, if a
>
> person or someone made a comment that is offensive… you could educate

them…even if they (referring to the audience or receiver of the story) didn't respond well, that's okay … [Participant 1]

Agency and communion. To comprehend the participants' views of agency and communion, it was important to have a contextual understanding of the participants' experiences of playing the role of a mental health advocate and sharing their story with others. This subtheme included the participant descriptions of taking ownership of their story, expressing the challenges they experienced in sharing their story and working with others in developing a network of support.

Throughout the sessions, the participants outlined their concerns about respect and ownership of their stories. As several of the participants did have experience sharing their stories publically and privately, they wanted to ensure that the reader understood the importance of thinking critically about how their story would be shared with others. This included discussing the precautions about how they deliver their story (e.g., online using social media or share in private); who they share the story with (e.g., not letting it be shared to others without consent); and the responsibility that accompanies sharing their story. One participant shared:

> …your story is ongoing and fluid …You can be as anonymous as you want…You don't have to tell 100% of your story…You own your story. Just because you have told it before doesn't mean you have to keep telling it…and how your story is shared is up to you and it should never be shared without your consent…Ownership comes as a responsibility, so think about how what you are saying could affect others and avoid content that could hurt or trigger others… [Participant 2]

Participants also acknowledged the emotional burden that can sometimes accompany having to advocate for mental illness when faced with stigma or feeling like they needed to always be the mental health advocate because of their personal experience with mental illness. One participant shared:

> …one of the things I was not expecting when I started having a conversation with my friends and family and the larger world eventually about this was that all of a sudden I became the person that people talk to if they wanted to know about mental health … If they needed help with their family member, their friend, or themselves, and I was not prepared for that and I don't think… that I handled it very well, until I got a handle on it, but I think … if somebody acts like an idiot and you have a conversation with them and they're still gunna be determined to act like an idiot, you can just like cut them out of your life, but if…you get dragged into helping someone and you don't feel like you have the skills to do it, it's almost a scarier experience. [Participant 5]

Participants also experienced a deep sense of responsibility and worry about sharing their story. They expressed feeling a sense of obligation to constantly share their story or be a mental health advocate because of their experience. One participant shared their experience of this:

> …the responsibility… just because you're going through this experience doesn't mean that you have that extra load on you to correct information out there…like it's your duty to be open all the time just because maybe you are an advocate and you might be open to an audience of people but …in your personal life… you don't have to (share)…there is a lot of…ways of "disclosing" therefore… it gives the idea

that… this is a burden…this is a responsibility. Therefore, you have to open up and it

doesn't really…it just feels like you are just gunna have to do it …begrudgingly

…dreadfully… [Participant 3]

Communion was seen as an opportunity for the sharer to be open and honest with

others about how they wanted be supported in sharing their story. This included the

participants discussing the importance of the sharer being assertive in asking for what they

wanted or needed in order to feel supported. Support in this context could be financial

(e.g., being compensated for their time), socio-emotional, professional, or just being left

alone. One participant shared, "…you have to think about …being assertive…so how do

you want to be supported or compensated…" [Participant 2].

Self-care and preparation. In this sub-theme *self-care* and *preparation* represented an

increased sense of personal choice and control over how the sharer could support themselves.

Participants reported ways in which their experience of sharing their story personally, privately

or publically had a strong impact on their ability to cope with the disclosure. In addition,

participants reported using specific self-care techniques and preparations in an attempt to protect

themselves from the potential negative responses and to secure the support they needed.

Participants reported that one of the biggest influences in building an ability to cope with

negative reactions, responses or rejections by the receiver of their story stemmed from their

ability to support themselves through preparation, such as thinking critically about the

motivation behind sharing their story. One participant shared:

… I think when it comes down to it, the end goal is to…have your desires and your

needs met and so that you feel more comfortable… so I don't really think that other

people should factor into this (the decision to share) at all and …it just seems

weird…because this isn't… from my understanding …this isn't…about how to
become an advocate or a public speaker… [Participant 5]

In addition to thinking about the motivation for sharing their story, participants also
highlighted the importance of considering several other factors, when sharing. This
included, but was not limited to: boundaries and privacy; knowing your limits; self-
assessment (checking your mood and readiness); audience reaction; level of readiness;
supports; and impact of intersectionality. One participant shared:

…I think it is better to have people…talk about assertiveness… and… how you deal
with conflict if you are being assertive… How would this affect the conversation…or
self-care? … I think for the consequences, thinking about that aftermath what could
happen potentially…(maybe) get…a lot of…support from people around you…or
maybe it'll make some people kind of weird. Just emphasize that you can't control
other people's reactions, but it's important to think about … [Participant 2]

Some participants reported that their ability to cope as outlined in previous sections
came from conducting personal research on their experience and searching for supportive
allies or groups (online or in person) that can offer a source of support or advice on sharing
their story (e.g., Youth-serving organization). In this context, an ally was understood as an
individual who may or may not have personal experience with mental illness, but does
want to help or provide support in whatever way they can. One participant offered their
advice on finding support before sharing their story:

I would say that it is even more important you're gunna need somebody else who
understands, who has been through it and can be on your side and in your corner

because if you only, and I know this won't happen, but if all of your friends have

identified as … "normies" and they don't really understand your experience. Sharing

your experience and talking about it more might make them uncomfortable and then

you might feel bad so…finding someone to talk about, how do I talk about this and

how do I tell my friends about this, and to a person rather than a booklet, would

probably be helpful and I mean…trying to find a friend or somebody in your

community. I don't mean go and hang out with Kevin Brail or something but…just

somebody who you have…who is accessible to you. [Participant 5]

Identity

One of the components in identity development is the ability to share one's story with

others as a means to connect and determine who we are in comparison to others. All participants

spoke to the impact that language had in how they identified themselves and how the public

identified them as individuals with mental illness. The theme of *identity*, including the subthemes

of *language* and *authenticity*, examined the barriers or bridges that participants experienced

when sharing their story as well as how to best develop this topic in the best practices guide.

When discussing the importance of language and authenticity in relation to identity, participants

highlighted the impact that negative stereotypes can have on how someone identifies themselves:

…defining yourself as mentally ill it creates stigma because it's just…I hate the term,

when you say you'd be "mentally ill" because …say Marie is a person who is open

about her mental illness. I feel if you put identity with mental illness, it's a weird

controversial thing, as in some people like that extension and some people don't…

[Participant 3]

Language. This subtheme outlined the impact that *language* had on representation and the development and expression of identity. To better understand how language could influence the development and expression of one's identity, it was important to consider the role that credibility played in the development of a manual or guide. Participants shared that when they reviewed Buchholz and Corrigan (2012) adult workbook and Corrigan and Lundin (2012) adult manual, their biggest challenge was looking past the language and tone used throughout.

Participants expressed that they wanted to use accessible and meaningful language that best represented themselves and their readers as youth with mental illness. The participants reported that the tone used within the manual portrayed a power-over ideology which left them feeling that there was little room for individual expression or preference— the author was the authority figure and the reader was the subordinate. One participant reflected on their views upon reading the manual:

> I felt like the book didn't end up helping me at all. I was trying to find a really nice
>
> way to say it, but I am not very good at doing that. I just thought that it was a little bit
>
> ridiculous…You were right to play devil's advocate (referencing a previous question
>
> I asked the participants). I felt like there were people that this probably applies to,
>
> but I didn't. I thought that it was kind of an enabling book… like saying it's okay to
>
> break from people that don't have the necessary language (referring to people using
>
> stigmatizing language for mental illness), but that doesn't mean you shouldn't…try
>
> to correct them in using … proper terms for it. So I felt like the whole book just
>
> didn't really change my perspective. It kind of just made me feel like, wow, we've
>
> come so far from this point. [Participant 1]

Participants reported that the use of labels both within Buchholz and Corrigan (2012) adult workbook and Corrigan and Lundin (2012) adult manual as well as in the general public also posed a challenge as they often found themselves wanting the freedom to choose their own way of expressing their identity. One participant shared:

> I've found that this book kind of focuses on having a mental illness, but I've never really looked at it that way. I look at it… I wrote down here as a general comment "having a life" and "what mental illness might have been a part of" but it's not like my mental illness affected my life … well actually it did, so that is not an accurate statement, but this (referring to her mental illness) is just like a small part of it… [Participant 1]

Participants discussed how identity was seen as more fluid than linear, as from their perspective, it was always changing. Participants expressed that the way the public saw or defined them as individuals with a mental illness was different than how they saw themselves. Additionally, participants also reported that the context and who they were sharing information with could also impact how they would define themselves. The purpose of sharing could change dramatically, such as sharing at school in order to get support, or sharing publically to break down barriers or stigma. One participant shared their experience:

> … I have always represented myself to highlight this strength that I am who I am and I find strength in that and it's not that I'm trying to be normal or convince people that I am normal. It's just, being exactly who I am makes me comfortable and I guess for me…it's how I define myself because… I've had formal bios and stuff written. It just really depends on who's in the room and what I'm doing…Would they be more

likely to listen if I list off the media that I've been in or would they just want to know

that I'm just a normal person like them? It really depends … It's just what you share

because you can share the same amount of stuff but just leave out stuff that may not

communicate the tone that you want to communicate. [Participant 5]

Authenticity. This theme represents the participants need to connect or disconnect from a

certain context, situation, person, or topic as a means to maintain their core beliefs. Participants

reported ways in which their experience of *authenticity* in the form of being "real", honest, and

open had a strong impact on their ability to connect or disconnect with others (with or without a

mental illness) when discussing mental illness. In addition, participants reported ways in which

the use of authenticity was imperative to the creation of a meaningful resource that both the

participants and the audience could relate to.

Participants reported that honesty and openness about an individuals' true experience

with mental illness (personal or relational) were vital components in establishing a connection

with the audience on the topic of mental illness. The challenge, however, was trying to find the

right balance between being too honest about the experience and running the risk of scaring the

audience (i.e., not sharing at all) or not being open enough about the experience that the audience

misses the message. Participants disclosed the challenges that they occasionally faced when

trying to find that a balance when sharing their story and being genuine when sharing their own

experience with mental health to others. One participant shared:

I think this captures one of the struggles that I've had in helping people disclose,

because it's true that not everybody will react like badly. However, some people do

and so it's like, do you tell them and then they probably might not disclose, or do you

not tell them and then they feel like wronged by you… [Participant 5]

Additionally, participants disclosed their belief that using a real story when discussing mental illness, be it sharing one's experience with mental illness or creating a best practices guide, helps to provide empathy *not* sympathy towards understanding mental illness. One participant shared:

> I think…hearing a personal story from someone versus getting a lecture on mental
>
> illnesses …It's easier for you to look at someone and think…this is actually real, this
>
> actually happened, rather than hearing about it… I think empathy makes things a lot
>
> easier to understand, whereas maybe when you read… a fact about mental health,
>
> you don't need to have sympathy around it. You need empathy. You need to…try to
>
> understand what someone might be going through rather than just…look at it from a
>
> different perspective of… feeling… [Participant 1]

The majority of participants reported feeling challenged by the use of a fictional or convoluted story of an individual with mental illness. They found it difficult to connect and stay focused on the underlying message of the story. Additionally, the participants reported that they felt strongly about staying true to authenticity when discussing mental illness. They did not want to misrepresent any of their audience members by creating a story they personally had no experience with. One participant shared:

> I think you should stick to writing what you know when it comes to speaking about
>
> stories that you know people will relate to because when I look at a book I want to
>
> see every, I want to see stories about transgendered people and people that are part of
>
> different minorities. But I would never write it myself because I don't think it's
>
> appropriate for me to write many perspectives other than my own when it's being
>
> used for this (creating new guide) because I can imagine what it would be like for a

female that might be exactly like me except she's a person of colour and I can't write

from that as much as I can imagine what it would be like. So I definitely think it

won't be authentic if I write it. [Participant 1]

Meaningful Vision

A successful, cooperative partnering between participants, researchers, and a national

youth organization is built upon the foundations of open communication and equality. It was

important to have an understanding of how the participants, national youth organization and

myself as the researcher collaboratively worked towards compromise and agreement of the final

product. The final theme, *meaningful vision*, highlighted the use of such a foundation in creating

a meaningful resource for youth on the decision to self-disclose about their experience with

mental illness. This included focusing on both the *process* and *product* in the creation and

development of the resource. When discussing next steps with respect to what the participants

thought should be done to move towards completing the final product, one participant shared:

> … I think it was important to all of us that we have some dedicated time that we can
>
> all work together and coming up with something new in a resource that you guys all
>
> feel really good about, that you're proud of creating, and that's useful and helpful as
>
> we move forward …We're going to be coming up with creating a resource for young
>
> people who are considering sharing their experiences in a public way. So we're
>
> gunna still refer to the manual and refer of course to your own experiences and your
>
> own knowledge and then figure out really how we want to compile that. What is it
>
> gunna look like? What's it actually gunna be? [Participant 6]

Product. In this subtheme the *product* draws attention towards the vision/purpose, expectations and concerns that all the participants expressed during the development of the final product. This included participants identifying the purpose of the new guide by outlining their expectations regarding the language, tone, content, and overall message that the final product would portray upon its completion, as well as voicing their concerns about the direction and content of the resource and its relatability to the audience.

All participants reported that the purpose of the final product was to create a resource that would aid youth in the decision to share their experience with mental illness to others and to provide additional support for self-care. Participants frequently expressed that they expected the final product to use accessible language and an accepting tone which would encourage engagement and relatability. Participants suggested that the ability to connect with the audience was vital in ensuring that the overlying message was received. One participant shared their opinion of the type of language that should be used in their best practices manual:

> I think the language in general should always point to the fact that it's about meeting
> your needs as opposed to keeping secrets from people**…**language that reflects best
> practice so it's supportive and inclusive, but also based off of what we know research
> wise and things to consider… I think the language (should) definitely reflect that if
> someone has a negative reaction, that it is not your fault. But think about how it
> could affect your relationships and … be realistic, but also fun… [Participant 2]

Participants reported that they wanted a manual that was supportive and inclusive of all youths' experiences with mental illness, which included the recognition of the impact that intersectionality plays in an individual's experience. Participants expressed that highlighting the

complexities of intersectionality allowed both the sharer and the audience the opportunity to gain

a deeper understanding of each person(s) experience with mental health. One participant shared:

> … I think there should be also something about intersectionality in sharing stories. A
>
> lot of people don't know that a lot of experiences are a bit different in how they
>
> affect you. Intersectionality is something that should, that tends to get looked over
>
> sometimes… There are so many cross ways between experiences and people have
>
> separate experiences so… having a mental illness is not a blanket term for
>
> everybody. Everybody has a different experience which is why telling your story is
>
> so important because, for me, it was really hard to tell my family because of cultural
>
> issues and some people might face the same thing, being a first generation Canadian
>
> and having trouble opening up about their story… [Participant 3]

Participants expressed concern over the use of Buchholz and Corrigan (2012) adult

workbook and Corrigan and Lundin (2012) adult manual in the development of the new guide as

they felt challenged by the language, tone, and overall message used. Participants frequently

reported the need to separate themselves from the adult workbook and manual as it did not align

with their vision, expectation, or overall message of the final product. Additionally, the

participants often reported that they possessed the expertise and knowledge needed to develop an

entirely new resource that not only aligned with their overall message of acceptance and freedom

of choice, but it would also be relatable guidance to youth with mental illness on the decision to

share their story. One participant shared:

> … I think this has been discussed before so I'm excited to…make some awesome
>
> fixes to it and improve it (referring to the workbook and manual), but I'm also
>
> challenged by the fact that I actually think we have more expertise…I think honestly

we can probably write something better than this (referring to the workbook and

manual)…It seems disingenuous to me right now to be working on somebody else's

work and when everybody in this room has such amazing experience and could craft

something better and I feel a little bit challenged by how holding…not being held

down by something that is existing…I think it's had its time and it's place and it

might be time to retire it to be honest…I'm sorry if that is offensive, but that's just

where I am right now. [Participant 5]

Additionally, despite the benefits of using Buchholz and Corrigan (2012) adult workbook

and Corrigan and Lundin (2012) adult manual as a reference point in the development of the new

guide, the participants reported a large number of barriers regarding their ability to connect with

the language and tone used by the authors as well as their ability to relate to the examples

provided by the authors. Participants frequently expressed the importance of using accessible

language and tone that would not alienate the audience whomever they may be (e.g., reader of

the guide or receiver of a youth's story). One participant shared:

I found there was a lot of higher level education words throughout, language

throughout the whole thing…if they were trying to target a younger crowd they

might not necessarily have the range of vocabulary…there's a lot of university style

language to it… [Participant 4]

Process. In this subtheme, *process* represented the level of motivation and participation the

participants displayed in working towards completing the final product. This included focusing

upon the ideas or suggestions that the participants presented to improve the adult workbook and

manual as well as noting the participant's motivation to stay on task in order to accomplish the

goals set out in each session. As noted in the previous sections, participants reported facing many

challenges in trying to stay objective during the revision of the adult workbook and manual.

Participants reported feeling constrained by the fact that their work would be tied to a workbook

and manual that did not align with their views. Participants shared:

> …I feel like the way these sections are named is dependent upon whether the idea of
>
> the main title would ever be changed because certain titles would work for example
>
> if I knew about sharing a story or about having a mental illness, but coming out
>
> proud and for some reason I have problems naming things because I feel like none of
>
> it is relevant to coming out… [Participant 1]

> Another participant shared:

> I'm just seeing a lot of the mentality and the style is kind of that regressive
>
> tone…There's regression everywhere…I realize that if we change the title we change
>
> a lot of almost everything about this book. [Participant 3]

All participants expressed the importance of allowing free expression. This included the

agreement that all concerns about the progress of the project would be discussed and everyone

would contribute equally to the progress of the revision and later development of the final

product. Participants reported that brainstorming different ways in which they could improve

Buchholz and Corrigan (2012) adult workbook and Corrigan and Lundin (2012) adult manual

allowed them the opportunity to be objective about what they truly wanted to accomplish with

their guide:

> So, just looking through the manual again, I can see where there's ideas that we can
>
> now use and again all the discussions that we had about it (referring to reviewing the

manual/workbook) …so just thinking about what *do* we wanna say if we don't want

to say this, then what *do* we wanna say to someone? [Participant 7]

To ensure that everyone was on the same page with respect to staying on task and

staying motivated, the participants and I took it upon ourselves to check-in with each other

as often as necessary. This included posing clarification questions, providing group

members with feedback on their ideas, discussing concerns and acknowledging ideas, and

check-in with group members individually to discuss how they thought the guide was

progressing. Some examples of asking for feedback from group members included: "…so

before we do that (referring to an activity) let's hear what you guys think needs to be

changed in terms of this section. So go ahead (participant 2)?" [Myself]; "I feel like

consider the method you'd like to share could be definitely just for delivery…what do you

think? [Participant 3]

Participants reported that checking-in with each other on how they felt about the

progress the group was making towards the final product validated their efforts. When

discussing how the group thought the final session went one participant shared:

> …it felt nice having an actual even if it's rough a word document…we've we created
>
> something after talking about it for so long it's nice to say all those things we wanted
>
> and what we didn't like and create something that works for us. [Participant 2]

Personal Journal and Follow-up Check-in

Participants were invited to reflect on their experience through weekly journal entries.

The purpose of both the reflective journals and follow-up responses were twofold. First, to

provide the participants the opportunity to use their voice and speak freely about their

experiences with mental illness and this project within a safe environment. Second, to have an

in-depth understanding of how the participants viewed the progress and process of their personal

journey in participating in the development of best practices for sharing your story. At the end of

each session the participants were asked to complete some reflection questions (outlined in

Appendix F) in the journals provided to them during the first session. All responses to the

questions were completely voluntary and the participants had the option to keep their responses

private or to share their responses with me at the end of the final session. Out of the five

participants, only two participants provided their responses to one of the four sessions. However,

due to the identifiability, the responses were left out from the analysis, leaving insufficient data

to use for the overall thematic analysis.

To ensure that each person had adequate opportunity to reflect on their experiences, the

participants were asked to respond to 14 reflection questions in either written or verbal format

during the final session. Similar to the journal reflections, the 14 questions outlined in (Appendix

E) were to provide the participants with an opportunity to reflection on their experience in the

project. The topics of the questions included the following: the youth's expectations and

experiences with choosing to disclose their story; how the youth viewed themselves both before

and after the project; how do they describe the process of disclosure; their view on accessibility

and inclusivity in relation to the development of new manual; the role of including youth with

lived experience in creating a new manual; and the overall take away message from their

experience on this project.

Upon reviewing the written and verbal responses from the questions, I found questions

six and 12 provided a meaningful summary of the participants' personal journey in contributing

to the development of this new guide as an expert. Question six spoke to the transformational

changes that the participant noticed from the beginning stages of the project to the end; *What, if*

any, changes have you noticed about yourself from where you started at the beginning of the

project to where you are now? Question 12 spoke to the importance of validating their

experience/expertise in the development of a manual for their fellow peers; *Why do you think it is*

important to include youth with lived experience in this project?

Overall, the participants reported that they did notice a change in their personal viewpoint

as well as an increased sense of knowledge. Participants' responses to question six ranged from

having a deeper sense of belonging—feeling like they were not alone, to wishing they had more

resources at the start of their own journey, to feeling that they could empower others to make

their own decisions about sharing. Some of the participant responses included the following:

> ... what I've noticed about my experiences in terms of this project, what I've noticed
>
> is how I wish I could have had something like this in my past because I wish I didn't
>
> have to do it on my own without barely any resources. So, I've noticed a lot about
>
> myself in terms of how I could have done things in the past, but now I also know that
>
> because I have a little bit more confidence in telling my story because I feel that I am
>
> stronger to defend myself… [Participant 3]

Another participant shared:

> I was a bit angry at myself then (referring the start of the project) … I had my times,
>
> but now I've gotten a lot better, I found myself per se, and now I'm accepted for who
>
> I am, people accept me for who I am and I am a lot happier and I am learning more
>
> and more each day with the project how to deal with the stuff and how to help
>
> people… The more people I talked about what I'm going through, I now know how

to deal with it and how to get help for it and it's just this big relief off my shoulders.

[Participant 4]

Overall, the participants reported that using real youth experts in the development of the

manual is what was really important to them. By focusing on their knowledge and expertise as

self-identified youth with mental illness, the participants expressed feeling confident in the

relatability of the final product. Participants' responses to questions included: a significant

emphasis on the fact that they were the experts; the importance of authenticity in creating

relatable examples; the ability to relate to the audience; and the opportunity for them to reflect

upon their own growth and share their knowledge. One participant shared:

Nothing about me without me. We are the experts in how we would want this

information to be presented and what needs to be there. If you want to use youth and

their stories, youth need to be at the table and they have been partners in a

completely equal manner. [Participant 2]

Another participant spoke to his experience with participating in this project and how it

influenced his view of including youth in the development of the manual:

I think it's important because some youth are going through what I am, and I may not

have as much experience as them, or I might have more, it really depends on your

experience level. If you are a part of a group that discusses topics like this (mental

illness), you can learn and build on the knowledge you already have and share that

knowledge with others who may not be a part of a group. Let's say if they come to

you and say "hey, I'm going through this what can I do?", then you have the

knowledge and you have something to help them. For example, telling them go see

your grad's counsellor or your social worker or go to a community centre and see if

there are community supports just like this. If it is someone who has more

experience, than they can help you learn something. [Participant 4]

Taken together, the participants highlighted the importance of learning from one

another as experts in their own experience and feeling more confident in their ability to aid

others in the journey of sharing their story.

Discussion

Using the lived experiences of youth with mental illness and disabilities, the current

project was a qualitative study that explored the process of disclosure for youth with mental

illness and disabilities in sharing their stories and developing a youth focused best practices

guide on the decision to disclose. To explore this process, three research questions were used:

(1) what are the youth's expectations of disclosing their story to others?; (2) what is the

experience of youth with mental illness and disabilities in choosing to disclose their story to

others?; and (3) what is important to youth about the decision to disclose or choosing to make

their experiences public? Information was collected using four group sessions (three, three-hour

sessions and one, six-hour session), one team meeting, one follow-up check-in (verbal and

written responses), and six individual personal journals (documenting both the participants' and

my personal experiences and observations of the sessions). In this section, the results from the

thematic analysis—outlining the three primary themes important to the participant's experiences

(developing the guide and sharing their story), the responses from the follow-up check-in during

the last session, and my field note observations will be discussed. This section also provides an

overview of the study's strengths and limitations before concluding with implications and areas

for future research.

Empowerment

The broader theme of empowerment outlines four prominent categories that participants

repeatedly spoke to as important to their experience in sharing their stories: *communication,*

education, agency and communion, and *self-care and preparation*. According to Munford and

Sanders (2015), a major component in connecting and enacting agency with youth is "having a

voice". This meant that youth were seen as equal partners in all aspects of agency which

included feeling that their opinions were heard, acknowledged, respected and that they were informed and involved in all aspects of the decision-making process that directly impacted them as they worked to produce the final product. Taken together, the four prominent categories highlighted by the participants in the current study speak to the intrinsic value of wanting their voice and experiences to be heard, valued, respected and recognized as an equal partner and agent for change.

For the participants in the current study, it was my interpretation that felt they were heard related to *communication* and the emphasis on the importance and power of choice in how their story would be delivered, as well as the type of language/tone used in relating to the audience in sharing their story and developing the best practices guide. Feeling valued as an equal partner was related to *education*, as participants discussed the importance of internal validation when educating themselves and others about mental illness and their experience with mental illness. They wanted to be valued for their knowledge and expertise in their lived experiences with mental illness. Feeling respected related to *agency and communion* as the participants highlighted the importance of taking ownership for their story, expressing the challenges they experienced in sharing their story, and working with others to develop a network of support. This included discussing the emotional burdens and the deep sense of responsibility and obligation in sharing their story and being seen as a mental health advocate. Finally, feeling recognized related to *self-care* and *preparation*, as participants discussed the ways in which their experiences of sharing their story personally, privately, or publically impacted their ability to cope with their decision and important role that self-care and preparations played in feeling an increased sense of personal choice and control over how they protected themselves against negative responses and found support.

From a feminist perspective, we did not want to perpetuate oppression. Thus, we felt it was important to take the time to listen, acknowledge and incorporate the participants' lived experiences and journey into the overall development of the best practices guide as an important part in reducing oppression and emphasizing empowerment. Moreover, Slay and Stephens (2013) stated that the best way to co-design an effective service for people is to have the consumers and professionals equally share the decision-making power, delivery of the services, as well as recognize, respect and value each other's unique contributions. That meant that the user's voice was heard, their assets and capabilities through their lived experiences were valued, nurtured, debated and most importantly, acted upon.

Identity

Youth with mental illness and disabilities face great challenges as they try to discover who they are and what their role is within society. Often they become labelled and sometimes their diagnosis becomes their identity. In the current project, the broad theme of identity and its corresponding subthemes of *language* and *authenticity* spoke to the barriers or bridges that participants experienced when choosing to share their story and how to represent this topic within the new guide. All participants spoke to the impact that *language* and *authenticity* had on how they identified themselves and how the public saw them as individuals with mental illness.

For the participants in the current study, one of the challenges that they faced in sharing their story was finding a means to step away from stigmatizing language and be able to express themselves without using labels that promoted stigma. Corrigan (2007) states that having a diagnosis can sometimes be seen as a double edged sword, as it is important for getting support, but it can also intensify public perceptions of people with mental illness. Moreover, reluctance to disclose, especially in relation to mental illness, is also based on the fear that an individual's

identity will be inaccurately associated with their diagnosis (e.g., Bos, Kanner, Muris, Jasen, &

Mayer, 2009; Seeman, 2013). However, the participants in the current study did recognize that

some youth may internalize their diagnosis, use it as a major part of their identity and may fall

prey to believing the public stereotypes. Conversely, they recognized identity as more fluid than

linear. They also stated that the way the public viewed them was often different than how they

saw themselves. One participant even went as far as stating that mental illness was one part of

who they are and that mental illness did not define their entire identity. Research on self-esteem

and self-stigma in relation to mental illness have found that individuals with mental illness, while

highly aware of the stigma and negative stereotypes that are associated with their group, did not

always internalize stigma (e.g., Corrigan, 2007;Corrigan & Watson, 2002; Corrigan & Rao,

2012; Corrigan, Watson, & Barr, 2006; Kranke, Jackson, Taylor, Landguth, & Floersch, 2015).

Taken together, it is possible that the participants' negative reaction to the language, tone and

stigmatizing labels used in the adult manual and workbook was their way of communicating that

self-stigma was not an issue for them. In fact, during the fourth session this was articulated by

one participant who, in conversation with the researchers about the general topic of stigma said,

"Stigma is not *my* problem – it is *yours…*" [Participant 1].

Research by Watson, Corrigan, Larson, and Sells (2007), suggests that the label promotes a

sense of belonging and positive identity knowing that others have similar situations. This finding

speaks to the emphasis of *authenticity* as a means for the participants to maintain their core

beliefs and to connect or disconnect from others when discussing mental illness. They often

reported ways in which the use of authenticity was imperative to the creation of a meaningful

resource that both youth with mental illness (i.e., sharer) and the audience could co-relate.

Kranke and colleges (2015) suggest that some individuals with mental illness become advocates

for change and feel empowered to overcome discrimination associated with the label of mental

illness. Thus, it is possible that the participants' emphasis on being authentic and "real" was their

way of using their own personal experience to advocate change for a better manual.

Meaningful Vision

Consultation and collaboration are also essential components to working successfully

with individuals with lived experiences with mental illness, especially when trying to create

meaningful support (DeLoach McCutcheon, et al., 2014; Munford & Sanders, 2015; Slay &

Stephens, 2013). To speak to cooperative partnering between stakeholders, the final theme of

meaningful vision, provided an in depth look at how the participants, YSO staff and myself

navigated the details needed in the development of the final product. Specifically, I focused on

both the *process* and the *product* that led to the creation of the final resource.

To develop an equitable and mutually beneficial partnership involving youth, researchers

must recognize that advancement cannot be possible without the perspective of youth's

experiences (e.g., DeLoach McCutcheon, et al., 2014; Slay & Stephens, 2013). This recognition

was evident in the subtheme of *product,* as participants identified their vision/purpose,

expectations and concerns regarding the overall message and content that would be included in

the final product. One of the most prominent concerns brought forward by the participants was

engagement and relatability as they expressed that the ability to connect with the audience was

paramount to their overall vision for the new guide. Research on identity development and self-

disclosure state that possible reasons why individuals may choose to disclose their stories is to

develop a connection with someone without having to engage in deeper kinds of personal

disclosure or communicating their understanding through meaning making (McLean, 2005).

Thus, it is quite possible that the participant's emphasis on connecting with the audience may

have been a reflection of the challenges they expereinced when trying to relate to Buchholz and

Corrigan (2012) adult workbook and Corrigan and Lundin (2012) adult manual.

Another way the participants discussed connecting with the audience was highlighting

the influence of intersectionality on an individual's experience with mental illness and sharing

their story. Specifically, participants spoke to the importance of showing the diversity of lived

experiences as they felt that the adult workbook and manual was too linear. Narrative research

suggests that the act of sharing one's expereinces with mental illness cannot only provide

constructive and realistic suggestions regarding how to be an agent for change, but it can also

help change stigmatizing attitudes towards stigmatized individuals (Corrigan & Rao, 2012;

Munford & Sanders, 2015; Young, 2009). Therefore, participants hoped that the discussion of

intersectionality could allow for both the discloser (sharer) and the audience (confidant) to gain a

deeper understanding of how mental illness has influenced their lives, thus potentially lowering

stigmatising attitudes.

Consultation and collaboration are essential components in working successfully with

individuals with lived experiences with mental illness, especially when trying to create

meaningful support (DeLoach McCutcheon, et al., 2014; Munford & Sanders, 2015; Slay &

Stephens, 2013). To better understand how these components contribute to the creation of a

meaningful resource, I wanted to focus on the *process* of developing the final product, which

included the participants' motivation and participation towards brainstorming ideas and staying

on task. For the participants, open communication with respect to brainstorming ideas,

checking-in, and discussing concerns about the progress of the project was imperative to

ensuring that everyone felt heard and could contribute equally to the final product. This idea,

worked quite well with the overall dynamic of the group and the progression of final product

during the last session as the participants readily discussed, organized and interpreted their

brainstorming ideas using thematic analysis resulting in a very comprehensive outline of the final

product. These results appear to align with the some of the literature on the involvement of

young people in research, specifically the idea that young people are very capable of interpreting

and conducting thematic analyses (i.e., looking for patterns in the data, contrasting differences,

discussing paradoxes and exploring significance) in search of finding meaning to the data they

collected (Coffey & Aktinson, 1996; Fleming & Hudson, 2009; Fleming, 2010). Therefore, it is

possible that the participants' intrinsic value about the final product came from the agreement to

allow all parties involved to openly discuss ways to improve the final product through

incorporating their skills, expertise, and experiences regarding the process of disclosure. That is

not to say, however, that the entire process was not met with its fair share of challenges.

Relationship to Research Questions

Overall, the results from the thematic analysis indicated that the participants expected to

share their stories, experiences and expertise, and that I would listen. In addition to the

expectation of sharing their stories, participants also expressed the need to find a sense of

community as a means to relate to others experiencing something similar or searching for

support. As well, they expected to work towards reducing stigma surrounding mental health, and

finally, they needed to feel that their voices were heard both as an equal partner in co-authoring

the best practices guide, as well as within the overall voice of the project. That is, participants

expected that the final product would be a representation of their expertise as youth with lived

experience of mental illness. In addition, participants also highlighted that their experiences in

choosing to share their stories were both positive and negative. Some spoke to feeling

empowered by how supportive their audience was, while others spoke to the challenges they

faced in trying to break through public stereotypes and promote empathy rather than sympathy. This was evident through the participants' reactions to the workbook and manual as well as their suggestions regarding how to improve the manual. Specifically, participants highlighted the importance of self-care, self-educating, educating others, type and tone of language as well as identity formation.

What was important to the participants in their decision to share or choosing to make their experiences public was the impact that both positive and negative reactions had on their outlook and identity. For some, the negative experiences in disclosing their story resulted in self-stigma, fear and isolation. Over time, however, they expressed that they felt empowered to self-educate and search for supports through community organizations. Others used their positive experiences to become advocates for change into stereotypes and stigma. Taken together, participants expressed that they hoped that they would be taken seriously as an expert of their own experience; that their opinion and experiences mattered; that the sharer would take the time to think critically about how the decision will impact themselves and others around them (i.e., both sides taking responsibility—sharer and receiver), and that others would feel supported and empowered by their journey.

Follow-up Check-in Responses

To better understand how mental health professionals and the general public can provide improved support and reduce stigmatizing attitudes for youth with mental health disorders and disabilities, it was important to understand the motivations and reasons for disclosing behind an individual with mental health issues (Bos et al., 2009; Chaudoir & Fisher, 2010; Corrigan & Rao, 2012; Ragins, 1994; Seeman, 2013). The purpose of collecting this data was to provide participants with adequate opportunity to reflect on their experiences as a whole. Thus, the

reflections from the participants regarding their experience were fairly self-explanatory. According to Slay and Stephens (2013), the best way to co-design an effective service for people is to have the consumers and professionals equally share the decision-making power, delivery of the services, as well as recognize, respect and value each other's unique contributions. That means the user's voice is heard, their assets and capabilities through their lived experiences are valued, nurtured, debated and most importantly acted upon (Slay & Stephens, 2013). It should be noted here that the purpose of the sessions with respect to the current project was less about providing a resource, but more about providing a non -oppressive space in which the participants could really focus on their experience and be heard. Thus, the participant responses provided a wide lens on their overall experiences in disclosing. That is, some participants discussed the challenges they faced in choosing to disclose because they did have a lot of resources to draw upon to assist them in coping with negative reactions. In contrast, some participants discussed feeling empowered by their experience because they developed a sense of belonging as they were able to discuss their experiences with a receptive and supportive audience, while others spoke to the importance of being heard (e.g., "nothing about me without me…": Participant 3).

Field Note Observations

Information from my field note observations suggests that there were three ways in which I potentially impacted the outcome of the data: *group dynamic, objective of the sessions,* and *language used*. As an active participant in the collection of my dataset, it was important to reflect and acknowledge how my beliefs, values and biases may have influenced the interpretation of the data or session. While it was ideal to try and separate each of the above noted influences, it is important to note that all of these topics were intertwined.

Group Dynamics. According to my field notes, there were two factors that influenced a change in the group dynamics. The first was my participation in the group as facilitator and observer and the second was the number of group members present in each session. In my role as a facilitator, I found that my participation did impact the participants' willingness to participate in the activities and provide responses to my questions. Specifically, I was far too active in my approach to organize and lead the sessions, which made the process too structured and rigid. The structured approach appeared to disempower the participants by limiting their freedom to act as equal partners in the revision process and lead the topics of discussion. In contrast, in my role as observer, I found that the non-active approach to facilitation impacted the group dynamic in a positive way by helping the participants feel empowered. This approach provided the participants with the freedom to take control over the session and cover topics they felt were necessary to move forward and develop the final product.

Furthermore, I also believe that the change in my approach to the sessions impacted the group dynamic because it impacted not only my comfort and confidence level as a researcher and facilitator, but also how I viewed my role within the group dynamic. As mentioned previously, I believed that my role during the first three sessions was to be the *director of information*—requiring me to take on a more directive and active role in leading the sessions, whereas during the last session my role was modified to be the *holder of information*—requiring me to take a less active and less directive role in leading and participating in the session. As a *director of information,* I believed it was my job to not only collect the most accurate data possible, but also to develop and lead the discussions and activities through using a directive and structured approach—reducing any chance of me missing any information presented by the participants. Comparatively, as a *holder of information*, I believed it was my job to use a less

active and non-directive approach to not only facilitate the session but also collect data—

allowing me to take on less responsibility in organizing, leading and facilitating the session as

well as allow me to focus more on observing the participants. Though I was not as eager to

change my approach during the last session, I knew that change (from both participants and

myself) was necessary to help move the project forward. Taken together, I believe that while

being a *director of information* offered me some comfort and predictability in being able to

control the session, I found it to be a bit stressful as I was met with a lot of resistance. Whereas

being a *holder of information*, required more flexibility on my part in taking on less

responsibility (reduced stress), offered less predictability (i.e., increased anxiety for me), but

allowed me to observe participant interactions through a different lens and provided less

resistance from the participants. Overall, both approaches had their advantages and

disadvantages in providing different ways of observing the participants process.

The second factor that influenced group dynamic was the number of participants. In each

session, the number of participants and staff members present often varied from three to five

(participants) and one to two (staff members). As such, I noticed that the number of individuals

present in each session impacted the dynamic of the group both through the topics discussed, as

well as the level of focus towards completing the session goals. When all five participants were

present in the session, the topic of discussion appeared to focus more on the overall end product

and how their expertise would be better utilized towards the development of a completely new

manual. Whereas, when there were three or four participants present, the group dynamic shifted

to how the topics of discussion were to be approached. That is, participants appeared to feed off

of each other's criticisms of the manual and often went off topic. In general, the participants

were very contentious about allowing each group member the opportunity to voice their

opinions.

In addition to the number of participants present in each session, I also noticed a change

in the group dynamic with respect to how the session was organized and how the group

communicated with one another (flow of conversation) when the distance participant engaged in

the session. Specifically, when the participant was virtually present in the session, I found myself

having to make slight modifications with respect to how the session was organized—adjusting

the length of activities to provide extra time for connecting and disconnecting with the

participant. Moreover, I also noticed a shift in how the group and I communicated with one

another when the distance participant was able to attend or not. That is, when the participant was

present the natural flow of conversation appeared to be disjointed at times to accommodate the

participant—inserting more pauses in the conversation and providing additional commentary

regarding the mood, reactions, or repeating participant responses to ensure that everyone was on

the same page. Whereas when the participant was not present the flow of conversation was more

natural as the group was able to use social cues to move the conversation forward. As such,

these slight modifications may have potentially impacted the outcome of the data as the process

was different for all of the participants.

Objective of the Sessions. In addition to considering how my involvement influenced

the group dynamic, I also considered my influence on the purpose and outcome of the sessions. I

focused upon how the varied expectations regarding the purpose of the sessions (i.e., mine vs.

the participants') influenced the topics of discussion. However, due to insufficient data collected

from the participants' journals, I was unable to compare the difference between expectations.

Thus, this section will focus upon my expectations of the purpose of the sessions both before and

after the restructuring meeting was called. Prior to the restructuring meeting, I expected the topics of discussion to focus on how the participants' experiences with the manual and workbook provided them with the ability to be objective in providing improvements to the manual. However, what I observed was that the participants' preoccupation with criticizing the manual made it difficult to re-direct the focus towards applying an objective view to improve the manual. Once they were able to vent their dislike for the manual and its negative impact on their decision to share their story, the participants spoke to their experiences and how the manual could be improved. After the restructuring meeting, I observed the participants taking on a more active role in leading the discussions and activities when I adopted a more passive role in facilitating the session. The revised dynamic appeared to empower and motivate the participants in creating the final product rough draft by the end of the last session. This result was significant in that we appeared to accomplish more in the final session than the first three combined.

Language Used. Finally, I reflected upon how my beliefs, values, biases and expectations could have influenced the type of language that I used with the participants in each session. Overall I found that the discussion regarding the use of inclusive language and the development of a glossary of terms familiar to youth positively impacted the rapport of the participants and YSO staff members. I also observed that the focus on language also impacted the participants' focus on the importance of using inclusive and relatable language in the final product.

Limitations

This study was primarily limited by its narrow participant demographic. Ideally, participants would have been more evenly distributed across gender, taken from different community organizations that work with youth with mental illness, and perhaps less informed

about supports within their respective communities and, therefore, more representative of

Ontario's youth population. With only five youth participants and two adult participants, the data

collected represents the unique experience of a small, well-resourced portion of primarily female

youth with lived experiences of mental health within a limited demographic.

Reasons for the narrow participant diversity could include: time of day or year that the

data was collected, as not all of the participants from the previous study participated; and

additional cultural, linguistic, structural and resource barriers that other youth with mental illness

who are not part of the dominant culture face. Goals of future research could include efforts

towards extending the invitations to, and providing accommodations for, youth who are not

affiliated with a national youth organization or well resourced within their respective

communities (i.e., could have some knowledge of community supports) and, thus, are more

representative of the Ontario population. Having a diverse sample more representative of the

Canadian youth population could benefit this line of research. However, it should be noted that

most if not all participants spoke to the role that the national youth organization played in their

experiences in disclosing to others and expressed concern over the barriers that youth with

mental illness may face by not having access to supports. In addition, dual relationships and the

availability of the participants could have impacted the responses from the participants, but not

in a negative way. We could not control for the types interactions that participants had outside of

the research study and we used other means of communication via phone or skype to include

participants who could not physically be present in the room. Additionally, as mentioned in the

previous sections there was one participant who joined the session via telecommunication. Given

the different approach in which this participant joined in the session as compared to the other

participants it may have potentially influenced the overall process of the sessions as well as the

flow of conversation during the sessions. Though it is difficult to determine the extent to which this participants approach or involvement within the session may have impacted the outcome of the data, future research could examine this further. A final limitation of this study is the risk of missing nuances in the data when conducting a thematic analysis, that is; factors that I considered to be less connected with the research questions were left unaddressed in the study.

Strengths

Strengths of this study include the flexible framework applied to the data, as it attended to the needs of the participants in order to create the final product. Thematic analysis allows for the natural emergence of categories through the participants' expression of emotions, experiences and expertise, thereby allowing me to capture the authentic, unique, and rich experiences of all the participants as they discussed the process of disclosure. As stigma is socially constructed and having an online presence is a vital component in combating stigma, having an online presence through the (Youth-Serving Organization) website was a key factor in not only providing accessibility to the resource but also accessibility to a broader community online. Finally, this study is the first of its kind to focus on providing a voice for the lived experiences of Canadian youth with mental illness on the process of disclosure. Working within a Canadian context and with Canadian youth was also a strength for this project, as it was important to make sure that the results and the resource developed from this project was relatable to the Canadian culture. This research highlights the current needs of Canadian youth with mental illness and hopes for the future of collaborative cooperation between youth with mental illness, community supports and academia in the development of relatable and meaningful resources on appropriate self-disclosure with the goal to inform future research and policy change.

Implications

Future Research. This study provided an outline of some prominent barriers and bridges to working with youth with lived experiences of mental illness and a national youth organization as experienced from the youth with mental illness perspectives. Past literature has painted youth as unconnected and detached or adverse in how they can be supported. However, recent literature and the current study has shown that in order to gain a greater understanding of the ways in which mental health professionals, the general public and community organizations can support youth with mental illness, we must look to youth as the experts and equal partners in how that support can be possible. It is recognized that while the current study may not have used a diverse population, future research can look to youth who may not be as well adverse in connecting with community organizations or initiatives as a means to highlight the needs of the greater youth population. Moreover, it is also suggested that the top 10 tips created by the participants in the current study (refer to Figure 2) can be used as a starting point in working with youth with mental illness to seek out community supports. Finally, future research can also use the top 10 tips in working with self-identified youth in building self-advocacy, assertiveness, self-awareness in relation to emotional needs, understanding their choices in their decision (e.g., delivery method, knowing you can change your mind) and thinking more critically about their decision to disclose.

Professional Practice. As a researcher and mental health professional, it is important to recognize that we must not make assumptions about an individual's experiences as it can promote biases and cloud our ability to remain objective. In addition to remaining objective, counsellors are also taught to use unconditional positive regard as it provides a safe space for the clients in which they feel accepted and respected without judgement or evaluation. In working with a vulnerable population such as self-identified youth with mental illness, I also found that

using a feminist approach helped not only to establish a good rapport with all the participants, it was imperative for all parties to feel that they had an equal part to play in determining the outcome of the final product. Once participants felt that they were equal partners, it was easier for me to understand what the participants wanted to discuss within the sessions (e.g., freedom of choice in the delivery and decision of disclosing), how they wanted the information to be received by their audience (e.g., accessible language and accepting tone), and what was their overall message that they were trying to portray (e.g., wanting to promote empathy about their experience not sympathy). Too often we jump to conclusions about what we think would be best for our clients or assuming we know what the issue is rather than asking them what they think would be best or what they would like to work on. As such, this research highlights the importance of slowing down and taking the time to recognize, respect and acknowledge youth's voice and lived experience with mental illness as only they can provide insight into what they want and need in order to feel supported.

Finally, the resistance that I experienced within the first three sessions of this study speaks to the importance of being self-aware when trying to advance the work we do with our clients based on our own agenda. When I was trying to push my own agenda forward I was met with a fair amount of resistance from the participants as I tried to get the participants to discuss topics that were not important to them or they were not ready to discuss. However, from that resistance I learned to be more flexible to better suit the needs of the participants which resulted in the completion of the final product (refer to Figure 2 in the Appendix for a copy of the 10 tips on sharing your story).

Closing Remarks

Literature on the topic of involving young people in the research process often provides mixed results as there are multiple benefits and the challenges that coincide with their involvement (Fleming & Hudson, 2009; Fleming , 2010). Some benefits of including young people in the research process include the ability to collect enriched data and greater opportunities for academic researchers to broaden their overall perspectives, as youth often challenge the purpose and language used within the research (Fleming & Hudson, 2009; Fleming, 2010). However, one of the biggest challenges that researchers face in working with young people include trying to control for power imbalance, as it can sometimes reproduce the experience of oppression and powerlessness that can often be associated to other areas of the young people's lives (Fleming & Hudson, 2009; Fleming , 2010). Thus, taking great care to involve youth in the research process cannot only help to protect against such issues from occurring, but can also ensure that their voices, opinions, and experiences are not overshadowed by the researcher's agenda or biases. Taken together, the overlying message of this research is that the best way to provide affective and meaningful resources for youth with mental illness is to involve youth with mental illnesses in the process. Additionally, it should be noted that youth with mental illness are the experts of their own experience. Thus, it is imperative for future research to recognize and appreciate the important role that their experience and knowledge contributes towards change. As equal partners in the process: "nothing about me without me…" (Participant 3).

References

Bazarova, N., & Choi, Y. H. (2014). Self-disclosure in social media: Extending the functional

approach to disclosure motivations and characteristics on social network sites. *Journal of

Communication, 64*, 635-657. doi:10.1111/jcom.12106

Bos, A., Kanner, D., Muris, P., Jasen, B., & Mayer, B. (2009). Mental illness stigma and disclosure:

Consequences of coming out of the closet. *Issues in Mental Health Nursing, 30*, 509-513.

doi:10.1080/01612840802601382

Buchholz, B., & Corrigan, P. (2012, August 26). Coming out proud to eliminate the stigma of

mental illness: Workbook for program facilitators and participants.

Burns, B., Phillips, S., Wagner, H., Barth, R., Kolko, D., Campbell, Y., & Landsverk, J. (2004).

Mental health need and access to mental health services by youths involved with child

welfare: A national survey. *Journal of the American Academy of Child & Adolescent

Psychiatry, 43*(8), 960-970. doi:10.1097/01.chi.0000127590.95585.65

Butler-Jones, D. (2011). *The chief public health officer's report on the state of public health in

Canada 2011: Youth and young adults--life transtion.* Ottawa: Public Health Agency of

Canada. Retrieved October 24, 2014, from http://www.phac-aspc.gc.ca/cphorsphc-

respcacsp/2011/index-eng.php

Canadian Mental Health Association (CMHA). (2014, October 25). *Fast facts about mental illness*.

Retrieved from Canadian Mental Health Association: Mental health for all:

http://www.cmha.ca/media/fast-facts-about-mental-illness/#.VEvmn_nF854

Chaudoir, S., & Fisher, J. (2010). The disclosure processes model: Understanding disclosure

decision making and postdisclosure outcomes among people living with a concealable

stigmatized identity. *Psychological Bulletin, 136*(2), 236-256. doi:10.1037/a0018193

Chew-Graham, C., Rogers, A., & Yassin, N. (2003). 'I wouldn't want it on my CV or their records':

Medical students' experiences of help-seeking for mental health problems. *Medical

Education, 37*(10), 873-880.

Coffey, A., & Aktinson, P. (1996). *Making sense of qualitative data.* London: SAGE.

Cohen, J. A., Berliner, L., & Mannarino, A. (2010). Trauma focused CBT for children with co-

occurring trauma and behavior problems. *Child abuse & neglect, 34*(4), 215-224.

doi:10.1016/j.chiabu.2009.12.003

Corrigan, P. (2004). Don't call me nuts: An international perspective on the stigma of mental

illness. *Acta Psychiatrica Scandinavia, 109*(6), 403-404.

Corrigan, P. (2007). How clinical diagnosis might exacerbate the stigma of mental illness. *Social

Work, 52*(1), 31-39.

Corrigan, P., & Lundin, R. (2000). *Don't call me nuts! Coping with the stigma of mental illness.*

Timely Park, IL: Recovery Press.

Corrigan, P., & Lundin, R. (2012, August 26). Coming out proud to eliminate the stigma of mental

illness: Manual for program facilitators and participants.

Corrigan, P., & Matthews, A. (2003). Stigma and disclosure: Implications for coming out of the

closet. *Journal of Mental Health, 12*(3), 235-248. doi:10.1080/0963823031000118221

Corrigan, P., & Penn, D. (1999). Lessons from social psychology on discrediting psychiatric

stigma. *American Psychologist, 54*, 765-776.

Corrigan, P., & Rao, D. (2012). On the self-stigma of mental illness: Stages, disclosure and

strategies for change. *Canadian Journal of Psychiatry, 57*, 464-459.

Corrigan, P., Watson, A., & Barr, L. (2006). The self-stigma of mental illness: Implications for self-

esteem and self-efficacy. *Journal of Social and Clinical Psychology, 25*(8), 875-884.

Cozby, P. (1973). Self-disclosure: A literature review. *Psychological bulliten, 79*, 73-91.

Creswell, J. (2009). *Research design: Qualitative, quantitative and mixed methods approaches* (3rd

ed.). Los Angeles: Sage Publications, Inc.

DeLoach McCutcheon, K., George, M., Mancil, E., Taylor, L., Paternite, C., & Weist, M. (2014).

Partnering with youth in school mental health: Recommendations from students. In

Handbook of School Mental Health (pp. 185-193). US: Springer.

Draucker, C. (2005). Interaction patterns of adolescents with depression and the important adults in

their lives. *Qualitative Health Research, 15*(7), 942-963. doi:10.1177/1049732305277859

Erikson, E. (1980). *Identify and the life cycle.* New York, NY: Norton.

Fang, K., Pieterse, A., Friedlander, M., & Cao, J. (2011). Assessing the psychometric properties of

the attitudes toward seeking psychological help scale–short form in Mainland China.

International Journal of Advanced Counselling, 33(4), 309-321.

Fleming, J. (2010). Young people's involvement in research: Still a long way to go? *Qualitative

Social Work, 10*(2), 207-223. doi:10.1177/1473325010364276

Fleming, J., & Hudson, N. (2009). Young people and research participation. In J. Wood, & J. Hine, *Working with young people: Theory and policy for practice* (pp. 114-126). London: SAGE.

Flett, G., & Hewitt, P. (2013). Disguised distress in children and adolescents "flying under the radar": Why psychological proglems are underestimated and how schools must respond. *Canadian Journal of School Psychology, 28*(1), 12-27. doi:10.1177/0829573512468845

Ganasen, K., Parker, S., Hugo, C., Steln, D., Emsley, R., & Seedat, S. (2008). Mental health literacy: Focus on developing countries. *African Journal of Psychiatry, 11*(1), 23-28. doi:10.4314/ajpsy.v11i1.3025

Gee, J. (2008). Identity as an analytic lens for research in education. *Review of Research in Education, 25*(2001), 99-125.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity.* Englewoods Cliffs, NJ: Prentice Hall.

Government of Canada. (2006). *The human face of mental health and mental illness in Canada 2006.* Ottawa, Canada: Minister of Public Works and Government Services Canada. Retrieved from http://www.phac-aspc.gc.ca/publicat/human-humain06/pdf/human_face_e.pdf

Gowen, K., Deschaine, M., Gruttadara, D., & Markey, D. (2012). Young adults with mental health conditions and social networking websites: Seeking tools to build community. *Psychiatric Rehabilitation Journal, 35*(3), 245-250. doi:10.2975/35.3.2012.245.250

Grotevant, H. (1993). The intergrative nature of identity: Bringing the soloists to sing in the choir. In J. Kroger, *Discussions on ego identity* (pp. 121-146). Hillsdale,NJ: Erlbaum.

Habermans, T., & Bluck, S. (2000). Getting a life: The emergence of the life story in adolescence. *Psychological Bulletin, 126*(5), 748-769. doi:10.1037//0033-2909.126.5.748

Henderson, S., & Gilding, M. (2004). 'I've never clicked this much with anyone in my life': Trust and hyperpersonal communication in online friendships. *New Media & Society, 6*(4), 487-506. doi:10.1177/146144804044331

Jorm, A. (2012). Mental health literacy: Empowering the community to take action for better mental health. *American Psychologist, 67*(3), 231-243. doi:10.1037/a0025957

Jorm, A., & Wright, A. (2008). Influences on young people's stigmatising attitudes towards peers with mental disorders: National survey of young Australians and their parents. *The British Journal of Psychiatry, 192*(2), 144-149.

Kessler, R., Berglund, P., Bruce, M., Koch, J., Laska, E., Leaf, P., . . . Wang, P. (2001). The prevalence and correlates of untreated serious mental illness. *Health Services Research, 36*, 987-1007.

Kjorstad, M. (2003). The current and future state of mental health insurance parity legislation. *Psychiatric Rehabilitation Journal, 27*(1), 34-42.

Klein, D., Shankman, S., Lewinsohn, P., & Seeley, J. (2009). Subthreshold depressive disorder in adolescents: Predictors of escalation to full-syndrome depressive disorders. *Journal of the American Academy of Child & Adolescent Psychiatry, 48*(7), 703-710. doi:10.1097/CHI.0b013e3181a56606

Kranke, D., Jackson, S., Taylor, D., Anderson-Fye, E., & Floersh, J. (2013). College student disclosure of non-apparent disabilities to recieve classroom accomodations. *Journal of Postsecondary Education and Disability, 26*(1), 35-51.

Kutcher, S., & Wei, Y. (2012). Mental health and the school environment: Secondary schools,

promotion and pathways to care. *Current Opinion in Psychiatry, 25*(4), 311-316.

doi:10.1097/YCO.0b013e3283543976

Lin, W.-Y., Zhang, X., Song, H., & Omori, K. (2016). Health information seeking in the Web 2.0

age: Trust in social media, uncertainty reduction, and self-disclosure. *Computers in Human

Behavior, 56*, 289-294. doi:http://dx.doi.org/10.1016/j.chb.2015.11.055

Link, B., & Phelan, J. (2001). Conceptualizing stigma. *Annual review of Sociology, 27*(1), 363-385.

Link, B., Cullen, F., Struening, E., Shrout, P., & Dohrenwend, B. (1989). A modified labeling

theory approach to mental disorders: An empirical assessment. *American Sociological

Review, 54*(3), 400-423.

Malmberg, K., Edborn, T., Wargelius, H., & Larsson, J. (2011). Psychiatric problems associated

with subthreshold ADHD and disruptive behaviour diagnoses in teenagers. *Acta

Paediatrica, 100*(11), 1468-1475.

Manne, S., Ostroff, J., Rini, C., Fox, K., Goldstein, L., & Grana, G. (2004). The interpersonal

process model of intimacy: The role of self-disclosure,partner disclosure, and partner

responsiveness in interactions between breast cancer patients and their partners. *Journal of

Family Psychology, 18*, 589–599.

Martin, J., Pescosolido, B., & Tuch, S. (2000). Of fear and loathing: The role of 'disturbing

behaviour', lables, and casual attributions in shaping public attitudes toward people with

mental illness. *Journal of Health and Social Behavior, 41*(2), 208-223.

McAdams, D. (1993). *The stories we live by: Personal myths and the making of the self.* New York:

Morrow.

McAdams, D. (2001). The psychology of life stories. *Review of General Psychology, 5*, 100-122.

McCain, M., Mustard, J., & Shanker, S. (2007). *Early years study 2: Putting science into action.* Toronto: Council for Early Child Development.

McLean, K. (2005). Late adolescent identity development:Narrative meaning making and memory telling. *Developmental Psychology, 41*(4), 683-691.

Mental Health Commission of Canada. (2009). *Out of the shadows forever.* Calgary, AB: Mental Health Commission of Canada.

Merikangas, K., He, J., Burstein, M., Swendsen, J., Avenevoli, S., Case, B., & Olfson, M. (2011). Service utilization for lifetime mental disorders in U. S. adolescents: Results of the national comorbidity survey-adolescent supplement (NCS-A). *Journal of the American Academy of Child and Adolescent Psychiatry, 50*(1), 32-45.

Miller, D., & Jome, L. (2010). School psychologists and the secret illness: Perceived knowledge, role preferences, and training needs regarding the prevention and treatment of internalizing disorders. *School Psychology International, 31*(5), 509-520. doi:10.1177/0143034310382622

Morgan, C., & Cotten, S. (2003). The relationship between internet activities and depressive symptoms in a sample of college freshmen. *Cyber Psychology & Behaviour, 6*(2), 133-142.

Mukolo, A., Heflinger, C. A., & Wallston, K. (2010). The stigma of childhood mental disorders: A conceptual framework. *Journal of the American Academy of Child & Adolescent Psychiatry, 49*(2), 92-103.

Munford, R., & Sanders, J. (2015). Young people's search for agency: Making sense of their

      experiences and taking control. *Qualitative Social Work, 0*(00), 1-18.

      doi:10.1177/1473325014565149

Narrow, W., Regier, D., Norquist, G., Rae, D., & Kennedy, C. &. (2000). Mental health service use

      by Americans with severe mental illnesses. *Social Psychiatry and Psychatric Epidemiology,*

      35(4), 85-90.

Noam, G., & Hermann, C. (2002). Where education and mental health meet: Developmentl

      prevention and early intervention in schools. *Development and Psychopathology, 14*(4),

      861-875. doi:10.1017.S0954579402004108

Oliver, M. (1992). Changing the social relations of research production. *Disability, Handicap and*

      Society, 7(2), 101-114.

Orme, J. (2003). "It's feminist because I say so!": Feminism, social work and critical practice in the

      UK. *Qualitative Social Work, 2*, 131-153.

Pescosolido, B., Fettes, D., Martin, J., Monahan, J., & McLeod, J. (2007). Perceived dangerousness

      of children with mental health problems and support for coerced treatment. *Psychiatric*

      Services, 58(5), 619-625.

Pinto-Foltz, M., Logsdon, C., & Myers, J. (2011). Feasibility, acceptability, and initial efficacy of a

      knowledge-contact program to reduce mental illness stigma and improve mental health

      literacy in adolescents. *Social Science & Medicine, 72*(12), 2011-2019.

      doi:10.1016/j.socscimed.2011.04.006

Public Agency of Canada. (2006). *The human face of mental health and mental illness in Canada.* Minister of Public Works and Government Services Canada. Ottawa, ON: Government of Canada.

Public Health Agency of Canada. (2013, February 7). *Mental Illness*. Retrieved from Public health agency of Canada: http://www.phac-aspc.gc.ca/cd-mc/mi-mm/index-eng.php

Pullmann, M., VanHooser, S., Hoffman, C., & Heflinger, C. (2010). Barriers to and supports of family participation in a rural system of care for children with serious emotional problems. *Community Mental Health Journal, 46*(3), 211-220. doi:10.1007/s10597-009-9208-5

Ragins, B. (2008). Disclosure disconnects: Antecedents and consequences of disclosing invisible stigmas across life domains. *Academy of Management Review, 33*(1), 194-215.

Ragins, M. (1994). Recovery: Changing from a medical model to a psychosocial rehabilitation model. *The Journal of the California Alliance for the Mentally Ill, 5*(3), 8-10.

Rüsch, N., Brohan, E., Gaddidon, J., Thornicroft, G., & Clement, S. (2014). Stigma and disclosing one's mental illness to family and friends. *Social Psychiatry and Psychiatric Epidemiology, 49*(7), 1157-1160. doi:10.1007/s00127-014-0871-7

Sakellari, E., Sourander, A., Kalokerinou-Anagnostopoulou, A., & Leino-Kilpi, H. (2014). The impact of an educational mental health intervention on adolescents' perceptions of mental illness. *Journal of Psychiatric and Mental Health Nursing, 21*(7), 635-641. doi:10.1111/jpm.12151

Sanders, C., Field, T., Diego, M., & Kaplan, M. (2000). The relationship of internet use to depression and social isolation among adolescents. *Adolescence, 35*(138), 237-241.

School-Based Mental Health and Substances Abuse Consortium. (2013). *School-based mental health in Canada: A final report.* Ontario: Mental Health Commission of Canada.

Seeman, M. (2013). When and how I should tell? Personal disclosure of a schizophrenia diagnosis in the context of intimate relationships. *Psychiatric Quarterly, 84*, 93-102. doi:10.1007/s11126-012-9230-6

Sentell, T., Shumway, M., & Snowden, L. (2007). Access to mental health treatment by English language proficiency and race/ethnicity. *Journal of General Internal Medicine, 22*(2), 289-293. doi:10.1007/s11606-007-0345-7

Shankman, S., Lewinsohn, P., Klein, D., Small, J., Seeley, J., & Altman, S. (2009). Subthreshold conditions as precursors for full syndrome disorders: A 15-year longitudinal study of multiple diagnostic classes. *Journal of Child Psychology and Psychiatry, 50*(12), 1485-1494. doi:10.1111/j.1469-7610.2009.02117.x

Slay, J., & Stephens, L. (2013). *Co-production in mental health: A literature review.* London: new economics foundation: nef.

Soor, G., Vukin, I., Bridgman-Acker, K., Marble, R., Barnfield, P., Edwards, J., & Bhalerao, S. (2012). The effects of gender on adolescent suicide in Ontario, Canada. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 21*(3), 179-185.

Spagnolo, A., Murphy, A., & Librera, L. A. (2008). Reducing stigma by meeting and learning from people with mental illness. *Psychiatric Rehabilitation Journal, 31*(3), 186-193. doi:10.2975/31.3.2008.186.193

Statistics Canada. (2002). *A profile of disability in Canada, 2001: Participation and activity limitation survey (PALS).* Ottawa: Statistics Canada: Housing, Family and Social Statstics

Divison. Retrieved October 24, 2014, from http://www.statcan.gc.ca/pub/89-577-

x/pdf/4228016-eng.pdf

Statistics Canada. (2003). *The daily--Canadian community healthy survey: Mental health and well-

being.* not provided: Statistics Canada. Retrieved November 26, 2014, from

http://www.statcan.gc.ca/daily-quotidien/030903/dq030903a-eng.htm

Statistics Canada. (2013). *Disability in Canada: Initial findings from the Canadian survey on

disability.* Ottawa: Social and Aboriginal Statistics Division.

Stice, E., Marti, C., Shaw, H., & Jaconis, M. (2009). An 8-year longitudinal study of the natural

history of threshold, subthreshold, and partial eating disorders from a community sample of

adolescents. *Journal of Abnormal Psychology, 118*(3), 587-597. doi:10.1037/a0016481

Stuart, H. (2005). Fighting stigma and discrimination is fightin for mental health. *Canadian Public

Policy, 31 (Supplement 1)*, 21-28.

Taylor, S., & Dear, M. (1981). Scaling community attitudes towards the mentally ill. *Schizophrenia

Bulletin, 7*(2), 225-240.

Valkenburg, P., & Peter, J. (2011). Online communication among adolescents: An integrated model

of its attraction, opportunities and risks. *Journal of Adolescent Health, 48*(2), 121-127.

doi:10.1016/j.jadohealth.2010.08.020

Vogel, D., & Wester, S. (2003). To seek help or not to seek help: The risks of self-disclosure.

Journal of Counseling Psychology, 50(3), 351-361. doi:10.1037/0022-0167.50.3.351

Waddell, C. (2007). *Improving the mental health of young children: A discussion paper prepared for the British Columbia Health Child Development Alliance.* Vancover, British Columbia, Canada: Children's Health Policy Centre.

Waddell, C., McEwan, K., Shepherd, C. A., Offord, D. R., & Hua, J. M. (2005). A public health strategy to improve the mental health of Canadian children. *Canadian Journal of Psychiatry, 50*(4), 226-233.

Wahl, O. (2002). Children's biews of mental illness: A review of the literature. *Psychiatric Rehabilitation Skills, 6*(2), 134-158.

Walker, J., Coleman, D., Lee, J., Squire, P., & Friesen, B. (2008). Children's stigmatization of childhood depression and ADHD: Magnitude and demographic variation in a national sample. *Journal of the American Academy of Child & Adolescent Psychiatry,, 47*(8), 912-920. doi:10.1097/CHI.0b013e318179961a

Wang, J. (2011). Service users`personal expereince and interpretation of mental illness: Oriental narratives. *International Journal of Social Psychiatry, 58*(4), 425-432.

Watson, A., Corrigan, P., Larson, J., & Sells, M. (2007). Self-stigma in people with mental illness. *Schizophrenia Bulletin, 33*(6), 1312-1318.

Wei, Y., & Kutcher, S. (2012). International school mental health: global approaches, global challenges, and global opportunities. *Child and Adolescent Psychiatric Clinics of North America, 21*(1), 11-27.

Wei, Y., Hayden, J., Kutcher, S., Zygmunt, A., & McGrath, P. (2013). The effectiveness of school mental health literacy programs to address knowledge, attituddes and help seeking among youth. *Early Intervention in Psychiatry, 7*(2), 109-121. doi:10.1111/eip.12010

Wei, Y., Kutcher, S., & Szumilas, M. (2011). Comprehensive school mental health: An intergrated 'school-based pathway to care' model for Canadian seconday schools. *McGill Journal of Education/Revue des sciences de l'éducation de McGill, 46*(2), 213-229.

Yang, L., Kleinman, A., Link, B., Phelan, J., Leed, S., & Good, B. (2007). Culture and stigma: Adding moral experience to stigma theory. *Social Science & Medicine, 64*(7), 1524-1535. doi:10.1016/j.socscimed.2006.11.013

Young, E. (2009). Memoirs: Rewriting the social constrction of mental illness. *Narrative Inquiry, 19*(1), 52-68.

Table 1

Five ways to disclose or not disclose

1. SOCIAL AVOIDANCE: Not telling anyone about your mental illness and avoiding

situations where people may find out about it. This could mean working or living in a

sheltered or supported work environment, where you only associate with other people with

mental illnesses.

2. SECRECY: Participating in work and community situations, but keeping your mental

illness a secret.

3. SELECTIVE DISCLOSURE: Disclosing your mental illness to selected individuals,

such as co- workers or neighbors, but not to everyone.

4. INDISCRIMINANT DISCLOSURE: Making the decision to no longer conceal your mental

illness; this does not mean, however, that you are telling everyone your story.

5. BROADCAST YOUR EXPERIENCE: Actively seeking out and educating people

about your experience with mental illness.

Note. Corrigan, P. W., & Lundin, R. K. (2012). *Coming out proud to eliminate the stigma of*

mental illness: Manual for program facilitators and participants. (Buchholz & Corrigan, 2012)

Figure 2. Top 10 Tips for sharing your story

Appendix A:

Western Research

Research Ethics

Western University Health Science Research Ethics Board
NMREB Amendment Approval Notice

Principal Investigator: Dr. Susan Rodger
Department & Institution: Education\Faculty of Education, Western University

NMREB File Number: 105261
Study Title: In My Own Words: Youth with Lived Experience Sharing Their Stories of Mental Health
Sponsor:

NMREB Revision Approval Date: July 03, 2014
NMREB Expiry Date: March 31, 2015

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Recruitment Items	Revised Recruitment Email	2014/07/02

The Western University Non-Medical Science Research Ethics Board (NMREB) has reviewed and approved the amendment to the above named study, as of the NMREB Amendment Approval Date noted above.

NMREB approval for this study remains valid until the NMREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario.

Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

Ethics Officer, on behalf of Riley Hinson, NMREB Chair

Appendix B

LETTER OF INFORMATION

In My Own Words: Youth with Lived Experience Sharing Their Stories of Mental Health

Introduction

We are a research team from The Centre for School-Based Mental Health at Western University's Faculty of Education. Dr. Susan Rodger is a professor and Melanie-Anne Atkins is a PhD student at the Faculty of Education. We are seeking to gain an understanding of the process by which youth with lived experience create, share, and reflect on their own experiences with mental health. As a young person who has had prior experience with *(Youth-serving organization)*, a non-profit organization that works alongside youth to support their mental health, we the research team would like to invite you to participate in this study.

Purpose of the Study

Youth with lived experience are often called to speak about their experiences with mental illness. However, no guidelines are commonly used that describe how to tailor this process to be in the best interests of youth during the process of telling. This study is designed so that we (the researchers) can collaborate with you (youth with lived experience) to participate in the process from beginning to end, including: making a decision about whether or not to tell your story; if you decide to tell your story, then formulating it; evaluating your experiences during the process; and providing recommendations for other youth who are considering sharing their stories, and who go on to decide that they will or will not, and for the organizations that invite them to do so.

If you agree to participate

If you choose to participate, we will ask for your permission to participate in a 2-week group that includes the researchers and 6-10 other participants. During Week 1, we will meet for 4 hours per day, for **three** days in a row. During Week 2, we will meet for 4 hours per day, for **two** days in a row. Each day, we will meet at the Faculty of Education in a private room. At the start of each session, you will receive two bus tickets and $20 to assist you with transportation to and from the Faculty. You are under no obligation to stay for the session after receiving your bus tickets and $20.

During Week 1 (3 days, 4 hours per day), we will work through a workbook called *Coming Out Proud to Eliminate the Stigma of Mental Illness* by Blythe A. Buchholz and Patrick W. Corrigan. This workbook is designed as a guide through the process of coming to the decision of whether or not to share your story. While working through this workbook, we will ask for your feedback on how to improve it to meet the needs of youth specifically. Each session will be audio-recorded.

At the end of Week 1, you will be invited to participate in an audio- and video-recorded interview or focus group, describing your experiences working with the workbook, and making the decision to share (or not to share) your story. You can choose whether or not to participate in this interview or focus group.

If you agree to participate but do not wish to be video-recorded, you can sit out of range of the camera. If you wish to participate but do not wish to be audio-recorded, we will give you the questions in written form, and you can participate by providing your answers to the questions in written form.

During Week 2 (2 days, 4 hours per day), you will be invited to create your story about your experience with mental illness in your own words, using whatever format you choose, including artwork, prose, poems, etc.

At the end of Week 2, you will be invited to participate in an audio- and video-recorded interview or focus group describing your experiences creating your story, in order to formulate recommendations for other youth storytellers and for the organizations who invite youth to tell their stories. Again, you can choose whether or not to participate in this interview or focus group.

If you agree to participate but do not wish to be video-recorded, you can sit out of range of the camera. If you wish to participate but do not wish to be audio-recorded, we will give you the questions in written form, and you can participate by providing your answers to the questions in written form; if your voice is captured on an audio-recording, your words will not be transcribed or included as part of the data.

This totals five, 4-hour sessions, over a two-week period if you decide to complete the whole process. You can withdraw your participation and stop attending the sessions at any time. You can decide not to come to a session, decide not to participate in the research taking place during any of the sessions, or refuse to answer any particular questions as you choose.

Confidentiality

The information collected will be used for research purposes only, and neither your name nor any identifying information will be used in any publication or presentation of the study results. We cannot guarantee confidentiality of information stemming from the group experience or focus group, but all members of the group will be reminded of the confidential nature of the study and asked to not talk about the group conversation outside of the group. All written information collected (story creations, survey responses, and interview/focus group transcripts) for the study will be kept confidential in the possession of Western's research team; only whole group findings and themes will be shared.

Risks & Benefits

There are minimal risks to this study; however, while reflecting on your experiences with mental health you might find that you need some support for your mental health. Therefore, at the beginning of each session, we the researchers will review the mental health resources available

to you at (Youth-serving organization) and in your community. If you experience psychological distress at any time during the program, you should leave the program and seek help immediately. As (Youth-serving organization) says on their website, "Sharing your story is important, however, if you are in crisis it may not be the right time. Your safety comes first. Get the help you need and deserve, and come back to submit your story at a better time."

This research can benefit organizations that seek out youth with lived experience by providing them with youth-informed recommendations that better speak to the needs of the young people they desire to support.

Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, refuse to share your story, or withdraw from the study at any time. If you withdraw from the study at any time, you are not obligated to attend any of the remaining sessions. Deciding to not participate, or withdrawing at any point from participating, will not have any negative consequences for you with respect to your relationship with (Youth-serving organization).

Questions

If you have any questions about the conduct of this study or your rights as a research participant you may contact the Office of Research Ethics, The University of Western Ontario. If you have any questions about this study, please contact Dr. Susan Rodger. This letter is yours to keep for future reference.

Sincerely,

The Research Team

Dr. Susan Rodger & Ms. Melanie-Anne Atkins

Appendix C

CONSENT FORM

In My Own Words: Youth with Lived Experience Sharing Their Stories of Mental Health

Dr. Susan Rodger & Melanie-Anne Atkins

Faculty of Education

Western University

I have read the Letter of Information, have had the nature of the study explained to me by a member of the research team listed above, and I agree to participate. All questions or concerns have been addressed to my satisfaction.

****Please initial your choice of the options below:

_____ YES, I agree to participate, to be audio-recorded, and to have my words transcribed from the audio recording during the 2-week program.

_____ YES, I am willing to participate in a **focus group** for research purposes during the 2-week program

_____ YES, I am willing to participate in an **interview** for research purposes during the 2-week program

_____ YES, I agree to be audio-recorded during the focus group or interview.

_____ NO, I do not agree to be audio-recorded during the focus group or interview.

_____ YES, I agree to be video-recorded during the focus group or interview.

_____ NO, I do not agree to be video-recorded during the focus group or interview.

_____ NO, I am not willing to participate in a **focus group or interview** for research purposes during the 2-week program.

Printed Name: _____

Signature: _____   Date:

_____

Name of Person Obtaining Informed Consent:

_____

Signature of Person Obtaining Informed Consent:

_____

Date: _____

Appendix D

Outline of the Five Sessions

Session 1

Length: 3 hours (4:00 pm - 7:00 pm)

Meeting place: (Youth-Serving Organization) office (YSO)

Date of meeting: January 23, 2015

My Goal:

My goal for the current session is to introduce myself and the study, to get to know the youth, ask the youth to reflect upon their experience with using the workbook in their decision to disclose and if they feel comfortable promote a discussion on the youth's expectations of disclosing their story both before and after using the workbook. That is, asking the youth if they feel comfortable to discuss any reservations they had about disclosing their story before and after using the workbook and examine what aspects of the book worked for them in their decision to disclose.

List of materials needed:

- Construction paper
- Chart paper
- Markers
- Consent forms
- Envelopes for the compensation
- Compensation for the youth (train tickets and money)
- Chart paper
- Pens
- Journals
- Work books and manual
- Computer for Skype

References:

Buchholz, B., & Corrigan, P. (2012, August 26). Coming out proud to eliminate the stigma of mental illness: Workbook for program facilitators and participants.

Corrigan, P., & Lundin, R. (2012, August 26). Coming out proud to eliminate the stigma of mental illness: Manual for program facilitators and participants.

Comments	Outline
	Introduction • Introduce myself provide some background about myself and qualifications • Ask everyone to introduce themselves

	Icebreaker game #1→ Go around the youth and ask them to say their name along with a funny story about their name
	Icebreaker game #2 → go around the room and ask the youth to say their name and state what their hope or expectation is for the sessions
	• Ask the youth to create name tags
	   o Explain: The purpose of creating the name tags is to help me remember your names
	• Introduce the study and what it is about
	   o Purpose of the study
	   o Outline the letter of information
	   o Participation parameters
	   o Compensation
	• Discuss the importance of self-care
	   o I want to let you know that I do understand that discussing some of these topics may bring up different emotions in everyone if anything causes you to feel distressed or if you need some air you don't need to ask you can go
	   o I also want to say that if you decide to get some air please know that you are not alone and if you are gone for a period of time then either myself, Heather, or Christine will come out to check on you to make sure you are ok
	• Introduce Parking Lot
	   o This will be used to jot down any ideas that may be a bit off topic or we may not have time to discuss the topic until the end of the session

	Check-in moment Answer any questions the youth might have
	Goals of the session • Work with youth to establish ground rules for each session (e.g., work collaboratively, create a safe space to share, listen to one another, etc.) • I have created a glossary for all of you which defines the academic terms that I have discussed previously o Ask the youth what term they would like to use in place of disclosure Glossary Terms ***Disclosure*** Disclosure is seen as an opportunity to build intimacy within personal relationships as well as develop a sense of self (Chaudoir & Fisher, 2010). ***Synonyms of disclosure*** Share| Reveal | unveil | Confess | Relate | Release | Divulge | Make known

		Types of disclosure • Self-disclosure is defined as any verbal information given (e.g., private feelings, thoughts, beliefs, or attitudes) about oneself to another person (Cozby, 1973; Vogel & Wester, 2003). • Selective-disclosure: the decision to reveal private information (e.g., mental illness) to a selected individual, such as a friend, family member, co-worker or neighbor, but not reveal the information to everyone (Corrigan & Lundin, 2012) • In discriminant disclosure: making the decision to no longer conceal your mental illness; this does not mean, however, that you are telling everyone your story (Corrigan & Lundin, 2012) • Self-report disclosure: to actively record or write personal information such as private feelings, thoughts, beliefs or attitudes about one's self with the intent to show or share with others
		• Discuss the parameters of the session, number of breaks, length of session, amount of time for discussion/reflection, etc. o At the start of each session the group will review the goals of the session and come to an agreement as to what will be discussed
		• Open discussion on the goals of the current session and the sessions following o Present my goals for the session and ask youth what their goals are
		BREAK

		Discussion
		 • Ask the youth to review the workbook they had completed in the summer
		
		 • Building on what you had started with Melanie-Anne in the summer I have compiled a list of things that all of you had mentioned that you did not agree with in reviewing the manual during the summer
		 • This list represents where I think we should start please take a look at the list and tell me if it still reflects what you would still like to work on
		
		 Phase 1
		 Lesson 1 Main issues
		 1. Two statements need to be added or emphasized:
		     a. **Disclosure is not a one-time process** – it is an ongoing journey that changes at each point of disclosure.
		     b. **Disclosure is a two-way street**: Both parties have rights, responsibilities, and expectations.

2. Phase 1 participants recommended that this section cover the following, in this order:

    a. **Your Disclosure Goal** →This should come first because it influences how you weigh the costs and benefits of disclosing

        i. **For example:**

- **Changing the face of mental illness**: decreasing the stigma of mental illness by challenging stereotypes and assumptions about what a person with mental illness looks like and is capable of achieving.
- **Changing the world**: Sharing your context and how the system has affected you can change the system…and the world!
- **Self-education**: To learn more about your own mental illness.
- **Necessity**: "I have to tell someone right now because I'm out of options to solve this problem myself"
- **Navigation**: Sharing your personal experience in order to find the 'right' kind of help that is better tailored to your needs.
- **Providing support to others**.
- **Advocacy**: For yourself and others.
- **Empathy**: Sharing your story to break down barriers to empathy.
- **Deepening emotional intimacy**: Between friends, family members, romantic partners, etc.
- **Catharsis**: Sometimes it's a relief "just to say it out loud". Phase 1 participants felt that 'coming out' with your story allows you to acknowledge your humanity – that no one is immune to difficult times.
- **It comes up**: When your personal experience is relevant and can help inform the topic of conversation.
- **To take control of your story**: "If they're going to have a story, I prefer it to be the real one"

    b. **Costs and Benefits** to disclosing (but they disliked the chart contrasting costs and benefits – they had no suggestion on how to improve this)

COST	BENEFIT
"You can't take it back" (presumably, the revised manual is	People understand you better (e.g., a greater feeling of

positioned to mitigate the costs of this. This is also related to a goal of disclosure: Taking control of your story)	authenticity. After 'coming out', youth feel freer to *be more of themselves*)
Exploitation of your story by others with competing interests	Validation
Feeling **"permanently vulnerable"** as a result of others knowing your story	Getting support
Discrimination (e.g., when an employer uncovers your story and is making a hiring decision)	Being able to "provide navigation" to resources for those who hear your story.
"**Getting too many stories back**" and feeling unequipped to respond appropriately	New friends

3. Phase 1 participants disagreed with the **overall negative tone** of this section. They felt that participants would almost certainly decide not to disclose as a result of completing this section.

If they feel comfortable ask the youth to discuss…
- Their expectations in choosing to disclose to another person before using the workbook
- Their expectations in choosing to disclose to another person after using the workbook
- Have your expectations in choosing to disclose changed since using the workbook? Why/why not?

BREAK

Journal reflections

Explain the purpose of the journals
- As you can see I have given you a journal
- The purpose of this journal is to provide you the opportunity to express how you feel about this whole process this could be in any form you choose picture, written format, collage, etc.
- At the end of the five sessions I would love with your permission to use your journal entries as part of my thesis which would highlight how you all felt during this process as I believe it is important for the reader to know how all of you truly felt about this stage of the project
  - I would collect all of your journals at the end of the last session with your permission and photocopy them and give them back to you
- I will ask that you please take the journals with you and bring them to every session, if you have any ideas during the week or would like to add additional entries please feel free to do so

	• Please complete a journal reflection on how you felt about the first session using the questions attached **Reflection Questions to get you started…** *Remember this is your reflective journal and there is no judgement so please feel free to be as honest as possible. Please attach any pictures, poems, recordings, collages, etc. to the document.* 1. What were you thinking about at the end of today's session? 2. What were you thinking coming into the session? 3. What do you think the most critical thing or topic that stuck with your today's session? 4. Was there anything that you would have liked to discuss further or was not addressed in today's session?
	Wrap-up of the session • Check-in on how everyone feels o How do they think the session went? o When you leave today what will you be thinking about? o I want to hear from each of you how you are going to take care of yourself tonight? o I want to hear from you if you are okay to leave if you're not that's fine we can chat ▪ If you are not in a good place, please stay and we can have a chat • Review parking lot • Provide a brief outline of what will be discussed in the next session • I just want to remind everyone about self-care I do recognize that some of the topics discussed today and in further sessions may cause you to have an emotional response as such I would like to ask if any of you would like to participate in a 5-minute grounding exercise or meditation

Session 2

Length: 3 hours (4:00 pm - 7:00 pm)

Meeting place: (Youth-serving organization) office (YSO)

Date of meeting: January 28, 2015

My Goal:

My goal for the current session is to work on improving lesson 1 of the workbook: Considering the Pros and Cons of Disclosing. Work on creating stories or using personal experiences should the youth feel inclined to highlight the pros and cons of disclosing to make it more relatable to youth.

Materials Needed:

- Chart paper
- Regular markers
- Journals
- Manual and workbook
- Computer for Skype

References:

Buchholz, B., & Corrigan, P. (2012, August 26). Coming out proud to eliminate the stigma of mental illness: Workbook for program facilitators and participants.

Corrigan, P., & Lundin, R. (2012, August 26). Coming out proud to eliminate the stigma of mental illness: Manual for program facilitators and participants.

Comments	Outline

	<u>Check-in</u>
	• Review what was discussed last week
	• Ask if anyone has any questions or queries about last week's session
	    ○ Discussed the expectation of disclosing before and after using the workbook
	• Discuss what was done in M-A's project in regards to lesson 1
	    ○ List improvements that were highlighted (phase 1- lesson1 – section 1)
	    [refer to session 1 outline]
	• Outline the goals of the current session
	    ○ Improving lesson 1
	        ▪ Reviewing Part 1-3
	    ○ Open the floor to youth suggestions on what we can discuss this session
	• Discuss the importance of self-care
	    ○ I want to let you know that I do understand that discussing some of these topics may bring up different emotions in everyone if anything causes you to feel distressed or if you need some air you don't need to ask you can go
	    ○ I also want to say that if you decide to get some air please know that you are not alone and if you are gone for a period of time then either myself, Heather, or Christine will come out to check on you to make sure you are ok
	
	GROUNDING/MEDITATION Suggestion

	<u>Questions</u> Answer any questions the youth might have Ask the youth if there is anything in particular they would like to discuss that was not discussed in the previous session Review Parking Lot from last week start new parking lot
	<u>Section 1- Discussion</u> • Ask the youth to discuss the reasons why they think the manual should be rewritten for youth?
	If they feel comfortable ask the youth… • How they define themselves? (e.g., do you Identify yourself as a person with or without a mental illness, are other parts of your life more central to defining who you are [I am a friend, sister, brother; I am loyal, smart, funny, etc.] • To discuss what their experiences with mental illness (if they feel comfortable)? • How can personality impact a youth's decision to disclose?
BREAK	
	• Highlight the issues the youth found with the workbook in phase 1 of the project ○ Issues with examples given in workbook **Issues with Lesson 1 section 1** **Activity:** If possible divide the youth into 2 groups ask the youth to create a background story for a male and female youth that is relatable or aspirational (i.e., a story that they would like to see in the workbook) • Ask one group to come up with a background story of a male youth with mental illness who **does** identify with having a mental illness • Ask the other group to come up with a background story of a female youth with mental illness who **does not** identify with having a mental illness
	• Ask the groups to share their stories with the group if they feel comfortable • Discuss the stories ○ How do these new stories you have created contribute to improving the workbook? • Why is it important to have these two perspectives (i.e., someone who does identify and someone who does not)?
BREAK	

<table>
<tr><td></td><td>

Section 2: Secrets are part of life

- Highlight the issue that the youth brought up in the previous project:
  - Phase 1 participants could not understand why this even needed to be said. They strongly advocated for the **elimination of this section** because of the degree of shame associated with the word 'secret'. They recommended it be replaced by a statement that affirms **everyone's right to privacy**.
- Given your recommendation for change…
- Create a statement that affirms everyone's right to privacy in the decision to disclose or not
- Why do you think this statement is important?

</td></tr>
<tr><td></td><td>

Section 3: Considering the pros and cons of disclosing

- Refresh youth on the purpose of this part of the workbook
- The purpose of the next activity is to discuss your experience with Section 3 of lesson 1
- Talk about what they suggested as possible improvements from phase 1 project

- Ask what they think of their improvements now? Have they changed?

Purpose of Section 3: Considering the Pros and Cons of Disclosing
Learning objectives
- There are both benefits and costs to coming out
- Only you can weigh them to decide whether it is worth coming out
- Costs and benefits differ depending on the setting; for example, at work vs among your neighbours

Suggestions by the Youth from Melanie-Anne's project

Lesson 1 – Section 3
4. Two statements need to be added or emphasized:
   a. **Disclosure is not a one-time process** – it is an ongoing journey that changes at each point of disclosure.
   b. **Disclosure is a two-way street**: Both parties have rights, responsibilities, and expectations.

5. Phase 1 participants recommended that this section cover the following, in this order:
   a. **Your Disclosure Goal** →This should come first because it influences how you weigh the costs and benefits of disclosing
      i. **For example:**
         - **Changing the face of mental illness**: decreasing the stigma of mental illness by challenging stereotypes and assumptions about what a person

</td></tr>
</table>

with mental illness looks like and is capable of achieving.

- **Changing the world**: Sharing your context and how the system has affected you can change the system…and the world!
- **Self-education**: To learn more about your own mental illness.
- **Necessity**: "I have to tell someone right now because I'm out of options to solve this problem myself"
- **Navigation**: Sharing your personal experience in order to find the 'right' kind of help that is better tailored to your needs.
- **Providing support to others**.
- **Advocacy**: For yourself and others.
- **Empathy**: Sharing your story to break down barriers to empathy.
- **Deepening emotional intimacy**: Between friends, family members, romantic partners, etc.
- **Catharsis**: Sometimes it's a relief "just to say it out loud". Phase 1 participants felt that 'coming out' with your story allows you to acknowledge your humanity – that no one is immune to difficult times.
- **It comes up**: When your personal experience is relevant and can help inform the topic of conversation.
- **To take control of your story**: "If they're going to have a story, I prefer it to be the real one"

b. **Costs and Benefits** to disclosing (but they disliked the chart contrasting costs and benefits – they had no suggestion on how to improve this)

COST	BENEFIT
"You can't take it back" (presumably, the revised manual is positioned to mitigate the costs of this. This is also related to a goal of disclosure: Taking control of your story)	People understand you better (e.g., a greater feeling of authenticity. After 'coming out', youth feel freer to *be more of themselves*)
Exploitation of your story by others with competing interests	Validation
Feeling **"permanently vulnerable"** as a result of others knowing your story	Getting support
Discrimination (e.g., when an employer uncovers your story and is making a hiring decision)	Being able to "provide navigation" to resources for those who hear your story.

	"**Getting too many stories back**" and feeling unequipped to respond appropriately	New friends

6. Phase 1 participants disagreed with the **overall negative tone** of this section. They felt that participants would almost certainly decide not to disclose as a result of completing this section.

<u>Activity</u>
If they feel comfortable ask the youth to discuss…
- How can we make the risks and benefits of disclosing more accessible or easier to understand for youth?

Suggestion:
- Examples either personal or made up that outline the costs and benefits of disclosing using youth experiences
    - E.g., in choosing to disclose to a friend Seija is concerned about not being able to take it back as he is afraid his friend will treat him differently.
- Do they think these stories or examples will help to reduce the overall negative tone of the section?

Journal reflection
Please remember to do your journal reflection in a word file (refer to outline in session 1 for journal questions)

Wrap-up of the session
- Check-in on how everyone feels
    - When you leave today what will you be thinking about?
    - I want to hear from each of you how you are going to take care of yourself tonight?
    - I want to hear from you if you are okay to leave if you're not that's fine we can chat
        - If you are not in a good place, please stay and we can have a chat
- Review parking lot
- Provide a brief outline of what will be discussed in the next session

GROUNDING/MEDITATION EXERCISE
- I just want to remind everyone about self-care I do recognize that some of the topics discussed today and in further sessions may cause you to have an emotional response as such I would like to ask if any of you would like to participate in a 5-minute grounding exercise or meditation

Session 3

Length: 3 hours (4:00 pm - 7:00 pm)

Meeting place: (Youth-serving organization) office (YSO)

Date of meeting: February 4th, 2015

My Goal:

My goal for the current session is to work on improving lesson 2 of the workbook: There are different ways to disclose. That is, discuss the youth's experiences with disclosing to others, and discuss how to implement the improvements in parts 1-3 of lesson 2.

Materials needed:

- Chart paper
- Regular markers
- Journals
- Manual and workbook
- Computer for Skype

References:

Buchholz, B., & Corrigan, P. (2012, August 26). Coming out proud to eliminate the stigma of
    mental illness: Workbook for program facilitators and participants.

Corrigan, P., & Lundin, R. (2012, August 26). Coming out proud to eliminate the stigma of
    mental illness: Manual for program facilitators and participants.

Comments	Outline

	Check-in
	• Review what was discussed last week
	• Ask if anyone has any questions or queries about last week's session
	• Discuss what was done in Melanie-Anne's project in regards to lesson 2
	    ○ List improvements that were highlighted for each section
	• Outline the goals of the current session
	    ○ Improving lesson 2
	        ■ Reviewing Part 1-3
	GROUNDING/MEDITATION EXERCISE

	Questions Answer any questions the youth might have Review Parking Lot from last week start new parking lot
	Section 1- Different ways to disclose • If the youth feel comfortable ask them to talk about their experiences with disclosing to others? • Ask what factors helped them to decide to disclose or not?

	Discuss/reflect upon section 1 • Review the workbook for this section (purpose) [Session 3- lesson 2] • What did they think of this section? • Highlight the improvements listed in MA project • Brainstorm different ways in which people choose to disclose o What are some of the ways in which people choose to disclose?
	Section 3 – lesson 2 activity (p.21) Main issues with the workbook from phase 1 (review with participants) **Activity (lesson 2- section 1)** (p. 21-22) in the workbook Part 1→ • Review the five ways to disclose in the workbook • Ask youth to brainstorm how we can show the reader that the five different ways to disclose are not steps Part 2→ • Ask the youth to collaboratively create a story of a youth who uses indiscriminate disclosure and broadcasting his/her experience regularly
	BREAK
	Section 2: To whom might you disclose? • Review the purpose of the section (Session 3 – Lesson 2-Section 2) Purpose of the section (p.25) • Ask youth to discuss what they thought of the section • Did they have any reservations about this section? • In what ways can this section promote a positive outlook for youth who are trying to determine who to share their story with? • Did anyone in particular come to mind when completing this section? **Activity** • List 5 different avenues (ways) in which youth can disclose their story to another person • Provide possible reasons as to why you think youth would use this avenue? • What do you think the risks and benefits are for using these avenues?

	Testing a person for disclosure **Activity** (5 minutes) Ask the youth to brainstorm 3 examples each of an instance in which the "receiver (person you are going to disclose to)" has handled sensitive topics in the past (5 minutes) ask them to explain why they choose those examples and how did it help them make their decision (5 minutes) What advice would they give to a friend who is trying to test their person (5 minute) discussion about the responses overall
**BREAK**
	Section 3: Others responding to your disclosure Explain worksheet 2.4 (are you able to cope with disclosure) Outline the suggestions discussed in MA project (Lesson 3-Part 3 issues) **Issues →LESSON 3: Telling Your Story** **Main Issues:** 1. Phase 1 participants preferred the story template from *The Center for Dignity, Recovery, and Stigma Elimination* because it is less restrictive and does not require all speakers to come to the conclusion that: "I, like all people with mental illness, live, work, and play just like you. So, please treat me the same. Do not view me based on any unfair stereotypes." 2. In Kyle's story, she does not acknowledge the ongoing process of recovery, which Phase 1 participants viewed as a critical flaw in the use of her story as an example for youth to base their story on. "Sometimes things are still hard" – for many people with lived experience, mental illness is never just a "thing of the past". 3. Because of time constraints, we did not get to cover Part 2 ("Coming Out Proud through SOLIDARITY and Peer Support") and Part 3("How Did It Go?") **Activity** Work with the youth to brainstorm different ways in which a youth can unpack (come to terms with) their experience of a disclosure gone badly Suggestions: 1. Provide examples of a statement that acknowledges the strengths in choosing to disclose 2. Provide possible/examples reasons why someone might not respond the way you hoped

	3. Create a flow chart linking the youth's need for disclosure → possible reactions good/bad from others → alternative resources available in (the local region) (or other areas) that can aid in disclosing 4. Provide other possible suggestions on different supports that have worked for the youth when they did not get the reaction they were looking for (coping strategies, supports, etc.)
	Journal reflection Refer to outline in session 1 for reflective questions

	Wrap-up of the session
	• Check-in on how everyone feels
	    o When you leave today what will you be thinking about?
	    o I want to hear from each of you how you are going to take care of yourself tonight?
	    o I want to hear from you if you are okay to leave if you're not that's fine we can chat
	       ▪ If you are not in a good place, please stay and we can have a chat
	• Review parking lot
	GROUNDING/MEDITATION EXERCISE
	
	• Provide a brief outline of what will be discussed in the next session
	• I just want to remind everyone about self-care I do recognize that some of the topics discussed today and in further sessions may cause you to have an emotional response as such I would like to ask if any of you would like to participate in a 5-minute grounding exercise or meditation

Session 4

Length: 3 hours (4:00 pm - 7:00 pm)

Meeting place: (Youth-serving organization) office (YSO)

Date of meeting: February 11th, 2015

My Goal:

My goal for the current session is to work on improving lesson 3 of the workbook: Telling your story. That is, discuss what is important to the youth about the decision to disclose or choosing to make their experiences public and what was their experience in completing lesson 3 (i.e., focus on part 2—coming out proud through solidarity and peer support and part 3 –how did it go).

Materials Needed:

• Chart paper
• Regular markers

- Journals
- Manual and workbook
- Computer for Skype

References:

Buchholz, B., & Corrigan, P. (2012, August 26). Coming out proud to eliminate the stigma of mental illness: Workbook for program facilitators and participants.

Corrigan, P., & Lundin, R. (2012, August 26). Coming out proud to eliminate the stigma of mental illness: Manual for program facilitators and participants.

Comments	Outline

	Check-in
	    • How is everyone feeling today?
	    • Review what was discussed last week
	    • Ask if anyone has any questions or queries about last week's session
	    • Outline the goals of the current session
	        o Discuss
	            ▪ Why the decision to disclose is important to the youth
	            ▪ How did they feel when they finally disclosed?
	            ▪ How did it go?
	MEDITATION EXERCISE/GROUNDING

	• Answer any questions the youth might have… • Discussed any missed items from last week's Parking Lot and start new parking lot

	Discussion – Part 1
	Ask the youth to think about the last time they shared their story with someone
	    • What is important to you about the decision to share or choosing to make your experiences public (e.g., at the end of phase 1)
	    • If you could provide one message to future youth who are deciding whether or not to share their story what would tell him/her?

	Discussion - Part 2
	    • Ask the youth to talk (if they feel comfortable) about their experience with their decision to disclose in the first part of the project
	    • If they were to retell their story again would the story be the same or different
	        o Why/why not?

	BREAK

Section 2 – <u>Coming out proud through SOLIDARITY and peer support</u>

- Review the learning objectives of section 2
- Define what solidarity means to me
- Ask the youth what they think about the idea of solidarity?
    - What are their expectations of standing in solidarity?
- What are some ways in which you have found support?
- Where can youth like yourself find support (e.g., peer or other)?
- Ask the youth to complete worksheet 3.3 and 3.4
- Review the Glossary from section 2 and the learning objectives

Glossary

<u>Definitions</u>
Solidarity has two meanings
1) Coming out is easier when I stand proudly with peers
2) I expect others to stand with me as I am proudly

Section 2: Coming out with Peer Support

<u>Learning objectives</u>
- Coming out can be easier when you have peer support
- There are many types and characteristics of consumer-operated services
- Identify how important different characteristics of consumer-operated services are to you

Coming out can be easier when a person decides to join together with others for support. This might be informally, such as joining a group of friends who have shared lives experiences. But, here we talk about a more formal collection of programs, often called consumer-operated services, which include self-help and mutual assistance programs, are perhaps the best kind of programs that promote empowerment. AS the name suggests, consumer-operated programs were developed <u>by</u> consumers <u>for</u> consumers. *Worksheet 3.3* on the next page lists several characteristics of effective consumer-operated programs. You task here is to review the list and rate how important each characteristic would be on the seven-point scale if you were seeking out a consumer-operated service
Please complete worksheet 3.3 and 3.4 (pg.43-45)

BREAK

Section 3 - <u>How did it go?</u>

- Review the learning objectives of section 3
- Ask the youth to complete worksheet 3.5 using a personal experience (steps to find out if the disclosure interaction was positive or negative)
(p. 50 -51)

	• Ask the youth to reflect upon their scores privately or within the group whichever is most comfortable • Ask the youth to discuss their experience was it positive or negative? ○ What suggestions or changes if any do they have on their approach to disclosing in the future? • Ask the youth if they feel comfortable to reflect upon their experience with choosing to disclose using different mediums • Why did they use that specific medium? • Did the use of a different medium such as posting it online, creating a poem etc. contribute in any way to the final decision to disclose or not?
	Journal reflection Refer to outline in session 1 for reflective questions

	Wrap-up of the session
	• Check-in on how everyone feels
	    ○ When you leave today what will you be thinking about?
	    ○ I want to hear from each of you how you are going to take care of yourself tonight?
	    ○ I want to hear from you if you are okay to leave if you're not that's fine we can chat
	        ▪ If you are not in a good place, please stay and we can have a chat
	
	GROUNDING EXERCISE
	• Review parking lot
	• Provide a brief outline of what will be discussed in the next session
	• I just want to remind everyone about self-care I do recognize that some of the topics discussed today and in further sessions may cause you to have an emotional response as such I would like to ask if any of you would like to participate in a 5-minute grounding exercise or meditation

Session 5

Length: 3 hours (4:00 pm - 7:00 pm)

Meeting place: (Youth-serving organization) office (YSO)

Date of meeting: February 18th, 2015

My Goal:

The purpose of this final session is to complete any unfinished work with the youth, provide the youth the opportunity to further discuss any of the topics covered or not covered in the previous weeks, and to receive feedback on their overall experience of participating both projects.

Appendix E

Modified outline for session 5 (created by the youth and Youth-Serving Organization):

In Our Words

Length: 6 hours (10:00am – 4:00pm)

Meeting Place: (Youth-Serving Organization) office

Date: Saturday March 7th, 2015

Goal:

To create/propose a resource for youth who are considering sharing their experiences with mental illness in a public manner. Youth will work off of considerations collected while reviewing the "Coming out Proud" resource as well as their own past experiences and expertise. The process of the resource creation will be documented in order to guide future research that focuses on youth mental health and involves youth as research partners.

Materials:

- Post it notes
- Markers
- Chart Paper

<u>Outline</u>

Check in: 10:00 a.m. – 10:30 a.m.

- Wait for everyone to arrive
- Check in: how is everyone feeling
- Briefly discuss today's goals
- Ice Breaker
  - o Think of a time a story (movie, book, TV show) has really impacted you and why?
1. Sticky note wall

<u>Goals</u>: For youth to identify important considerations for the resource and have these sorted into key themes. These can include what information should be in the resource and how the information is presented.

- First individually, then in partners
  - o brainstorm issues that need to be considered/important to be included in resource
    - ▪ Both in terms of tone and how information is presented (e.g. language) and important practicalities/considerations for youth sharing their story
    - ▪ Create sticky notes
  - o Put sticky notes on wall to see patterns and themes

  ▪ From that we can sort them into themes

BREAK

   2. Format Discussion

Goals: Weigh the costs and benefits of different forms of presenting the information (e.g. text, video, info graphic). Discuss options in terms of how to best convey information to the specific target audience.

  - Discussion points:
    ○ Target audience = youth who are considering sharing their story in a more public manner
      ▪ How are they likely to access the information?
      ▪ What are they likely to invest time in
      ▪ How are they likely to absorb the information?
  - Break in groups/partners
      ▪ Brain storm ideas for how this resource could be presented
      ▪ Provide groups with chart paper and markers
        • Can create visuals or text representations
  - Join back into large group and discuss options
      ▪ Possibly come up with consensus of one format/ hybrid/ multiple formats

Lunch – 30 minutes

   3. Content Discussion and Creation

Goal: To create content for the decided upon resource in a manner that utilizes youth adult partnership, combining youth experience and expertise with clinical knowledge.

  - Review sticky board – this contains content and themes
  - Review chosen format
  - Decide on how group wants to create content
    ○ break into small groups
    ○ as a group
    ○ Individually – either in private or throughout group discussion

  - Bring content together – think about how it can form a cohesive picture

   BREAK

   4. Creation

Goal: To discuss what final resource should look like and finalize what group is able to create given time constraints.

- Again, youth will decide best manner to conduct final activity
    o Either group, small groups, individually
- Group should reconvene with enough time to bring together project

3:25 p.m. - 4:00 p.m.

Wrap-up and check-in

- Give youth an opportunity to present feedback on the day and the project as a whole
- check in on whole group
- Questions to follow-up and check-in:

1. What are the youth's expectations of disclosing their story to others?
2. What is the experience of youth with mental illness and disabilities in choosing to disclose their story to others?
3. What is important to the youth about the decision to disclose or choosing to make their experiences public?
4. Please describe yourself before this project started?
5. Please describe yourself now?
6. What if any changes have you noticed about yourself from where you started at the beginning of this project to where you are now?
7. Has your view on the process of disclosure changed at all since the start of this project?
   *Note additional questions were added to this list later on in the day on March 9th, 2015

- wrap up project
    o Ways to stay involved
    o What can be done with resource created/proposed?

Appendix F

Follow-up Check-in Questions

Name: _____   March 9th, 2015

<u>INSTRUCTIONS</u>:

The purpose of the questions listed below are to help provide some insight regarding your personal experience in working on this project and the process of sharing your story. There are no right or wrong answers to these questions as they are about your own personal experience. Please feel free to be as honest as you can in providing your responses to the questions. There are no page limits to your responses.

<u>QUESTIONS TO DEBRIEF</u>:
1. What are the youth's (your) expectations of disclosing your story to others?
2. What is your experience as a youth with lived experience in choosing to disclose your story to others?
3. What is important to you as a youth with lived experience about the decision to disclose or choosing to make your experiences public?
4. Please describe yourself before this project started?
5. Please describe yourself now?
6. What if any changes have you noticed about yourself from where you started at the beginning of this project to where you are now?
7. Has your view on the process of disclosure changed at all since the start of this project?
8. *What does accessibility mean to you?*
9. *Why is accessibility important to think about?*
10. *What do you think should be included in the new manual to make it inclusive for everyone?*
11. What do you think the purpose of the manual is?
12. Why do you think it is important to include youth with lived experience in this project?
13. Is there anything else that you would like to share?
14. What would your take away message be from this whole project/experience?

Appendix G

Journal Reflection Questions

Reflection Questions to get you started…

Remember this is your reflective journal and there is no judgement so please feel free to be as honest as possible. Please attach any pictures, poems, recordings, collages, etc. to the document.

1. What were you thinking about at the end of today's session?
2. What were you thinking coming into the session?
3. What do you think the most critical thing or topic that stuck with you in today's session?
4. Was there anything that you would have liked to discuss further or was not addressed in today's session?

Curriculum Vitae

Name:	Caryl-Anne Stordy
Post-secondary Education and Degrees:	Western University London, Ontario, Canada 2014-2016 M.A. Counselling Psychology Wilfrid Laurier University Waterloo, Ontario, Canada 2010-2012 M.A. Developmental Psychology Wilfrid Laurier University Waterloo, Ontario, Canada 2005-2010 B.A. Psychology (Honours Research Specialist)
Honours & Awards:	Faculty of Graduate and Postdoctoral Studies Scholarship 2010-2012 William and Marion Marr Graduate Award 2010
Related Work Experience:	Psychology Intern/ Counsellor Thames Valley District School Board (TVDSB) 2015- 2016 FASD- Support Mentor Fetal Alcohol Spectrum Disorder (FASD): A Night Out Group, London Family Court Clinic, London, ON 2015 – 2016 Group Facilitator Friends for Life Program, Royal Roads Public School, Ingersoll, ON Thames Valley District School Board (TVDSB) 2016

Publications and Conference Presentations:

Stordy, C-A. (June, 2014). Examining the impact of eliminating door-to-door mail delivery to vulnerable population groups, Key note speaker/Power point presentation at the Canadian Union of Postal Workers (CUPW) National Human Rights Conference, Ottawa, Ontario, June 22, 2014.

Lee, J., Kotsopoulos, D., & **Stordy, C. A**. (2012). Mathematically-relevant input during play of a caregiver with a visual impairment and her toddler. *International Journal of Early Childhood, 44* (1), 71-90. Doi: 10.1007/s13158-011-0040z