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Working with Youth as Stakeholders in Mental Health System Transformation: An Institutional Ethnography of a Service Organization in ACCESS Open Minds

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Abstract

As national system- and research-agendas invest heavily in the improvement of youth mental health services delivery, the discursive and policy impetus for the inclusion of youth as advisors has increased. However, we know little about the work of youth engagement (YE) in the everyday realities of a care-delivery organization. Does the engagement of youth advisors ultimately inform care?

This dissertation addresses the knowledge concerns of YE with a detailed account of the experiences of youth advisors, service providers, and an organization in the process of services reform. I used institutional ethnography to (1) reveal the day-to-day work of engaging young people as advisors to a mental health services delivery site; (2) examine the linkages and tensions between the discourse of YE and its realities in practice; and, (3) understand the processes by which youths' knowledge is articulated and admitted to organizational decision-making.

Fieldwork consisted of meeting observations and interviews with service providers and youth advisors, and a discourse analysis of YE practice texts to understand how their discursive framings coordinate local work.

Detailing engagement work made visible how service providers negotiate between a ruling discourse of engagement and the realities of mental health services delivery. They adapt to and resist problematic elements in the ideology of engagement, including its individualizing rhetoric and the omission of structural and social considerations. At the same time, they employ a youth-centred orientation made concrete by the youth advisors, using it to alter established organizational processes that have excluded youth as knowers from the institution of healthcare.

Findings from this study were analyzed in light of recent work on epistemic injustice. This proved to be a useful lens, making more precise whether and how YE makes a difference to youth, the organization and the culture of mental healthcare.

My findings underscore the necessity of framing YE as the labour of epistemic inclusion of youth in the design of formal systems of care. In telling this story of YE work at one service site, I suggest a new pathway for the operation and evaluation of engagement, as underpinning appropriate care and, ultimately, health equity.

Keywords

Mental health, participation, patient engagement, youth engagement, institutional ethnography, mental health services reform

Lay Summary

Alongside national investments in the improvement of youth mental health, enthusiasm for youth engagement has increased. However, we know little about what it means to engage youth as advisors of a care-delivery organization. Does the engagement of youth advisors ultimately inform care?

This dissertation addresses the knowledge concerns of YE with a detailed account of the experiences of youth advisors, service providers, and an organization in the process of services reform. I used institutional ethnography to (1) reveal the day-to-day work of engaging young people as advisors to a mental health services delivery site; (2) examine the linkages and tensions between the language and ideals of YE and its realities in practice; and, (3) understand the processes by which youths' knowledge is admitted to organizational decision-making.

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Co-Authorship Statement

Eugenia Canas completed the following work under the supervision of Dr. Helene Berman and Dr. Nadine Wathen, and the advisement of Dr. Srividya Iyer. All dissertation committee members have/will be co-authors on publications resulting from the chapters of this dissertation.

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Chapter 1

Chapter 1: Introduction

National policy and research agendas have begun to prioritize mental health service delivery. With an emerging emphasis on youth mental health, the impetus for the inclusion of young people as advisors and co-creators of system reform is increasing rapidly. However, we know little about the work of including youth perspectives — what they know of mental health and mental healthcare — within the everyday realities of a care-delivery organization. What does youth engagement (YE) look like in practice? In what ways does it impact the development and delivery of care? These are urgent questions requiring rigorous empirical examination.

This study takes a health information science perspective, investigating a multi-disciplinary context to understand how value is accorded to a particular type of knowledge, namely the perspectives of young people. This is a novel approach to investigate youth engagement; one that brings important new knowledge to this emerging priority in health system reform.

Institutional Ethnography (IE) was selected as an ideal methodology for examining the research questions posed in this dissertation. IE is a method developed in the field of sociology that creates a descriptive understanding of how certain forms of knowing can replace, undermine and also uphold other forms of knowing (Smith, 1987). As a method of inquiry, IE makes visible how the everyday world of people's experiences is "put together by relations that extend vastly beyond the everyday" (Smith, 2005, p. 1). IE scholars have previously described how workers in mental health services enact processes of empowerment of persons with lived experience of mental illness (Townsend, 1996). More recently, Griffith and Smith (2014) examined how changes happen in the direct-service work of organizations delivering mental health services to people. In keeping with this approach, I focused on the work of service providers as they interact with youth advisors, and sought to describe how their experiences in the local setting add to our understanding of youth engagement in practice.

IE is grounded in the everyday. It examines in detail the actualities of people's daily experiences to describe "work processes" (Smith, 1987). Complementing this grounding, IE frames analysis within a macro understanding of trans-local activities, discourses and values, which are termed 'ruling relations' and are understood to coordinate the daily work of people from afar (Smith, 2002, 2005; DeVault, 2006).

In this chapter, I contextualize the relevance and urgency of this inquiry, describe its setting, and set out the foundational theoretical constructs that informed the study.

Relevance

The mental health of Canadian youth is a national priority (Gilmour, 2014; Kirby & Keon, 2006). Up to 70 per cent of young adults living with mental health problems report that the symptoms started before the age of 25, and 50% before the age of 16 (Kessler et al., 2005). In Canada, 18.5% of youth aged 15 to 24 are affected by mental and substance use disorders (Pearson, Janz, & Ali, 2013). The highest rates of mood disorders (8.2%) and substance use disorders (11.9%) are reported by youth aged 15 to 24 (Pearson, Janz & Ali, 2013). Suicide is the second leading cause of death among 15 to 24 year-olds, and is responsible for one in five of all deaths in this age group (Bennet et al., 2015; Mental Health Commission of Canada, 2013).

The incidence of depressive and anxiety disorders among this population is considered a public health concern (Nguyen, Fournier, Bergeron, Roberge, & Barrette, 2005). An estimated one-half of Canadians ages 19 to 24 with suicidality have not sought mental health treatment (Cheung & Dewa, 2007). Only 20 to 25% of Canadian youth in need of help currently access any mental health services (Cheung & Dewa, 2007; Wang et al, 2005). In Ontario, between 18% and 22% of children and youth met criteria for a mental disorder. but less than one-third had contact with a mental health provider (Georgiades, Duncan, Wang, Corneau, Boyle, 2019).

There is universal scholarly consensus that our current mental healthcare system must transform to address youth mental health. Such reform is grounded on the acknowledgement of the impact of mental illness, calls for increasing and diverse forms of evidence (Bartram et al., 2012; Malla et al., 2018b), and a recognition of the need for improved services (Butler-

Jones, 2009; Georgiades, et al., 2019; Gilmour, 2014). The last two decades have seen an increasing global and national knowledge base on the state of youth mental health, along with various levels of commitment towards systems improvement (Iyer et al., 2015; Henderson, Chaim, & Brownlie, 2017; Patel, Flisher, Hetrick & McGorry, 2007; Waddell et al., 2019). The stakes are high: scholars identify that unmet need for services can interfere with other domains in the lifecourse, including educational and work attainment, and the development of relationships (MacLeod & Brownlie, 2014; Patton et al., 2016). Federal and provincial bodies in Canada acknowledge the human costs of mental illness, noting that untreated mental health issues in early adulthood may indicate increased risk of developing severe and enduring mental health problems throughout the life course (Freeman et al., 2011; Mental Health Commission of Canada, 2009). They also articulate such impacts in terms of national societal and economic costs (Lim & Dewa, 2008; Mental Health Commission of Canada, 2013; Smetanin et al., 2011).

Evidence of incidence rates and life-course impacts lends strong support to the need for multifaceted responses to lowering stigma, increasing public health promotion and systems-navigation education, and improvements in the appropriateness of care. However, concern about the capability of the mental health system to respond to the needs of children and youth has featured large in reports at national levels (Auditor General of Ontario, 2008; Bartram et al., 2012; Kirby & Keon, 2006; Ontario Ministry of Health and Long-term Care, 2011; Romanow, 2002). Pathways to mental healthcare for children and youth have been deemed long and overly complex (Anderson, Fuhrer, & Malla, 2013; Halsall et al., 2019; Iyer et al., 2015; MacDonald, Fainman-Adelman, Anderson, & Iyer, 2018). Many scholars in this area assert that the system's shortcomings include a lack in access to timely and appropriate care, a lack of youth and family engagement, and siloed-thinking grounded in diagnostic categories that predominantly inform care (Halsall et al., 2019; Malla et al., 2018). A systematic review of youths' access to health services in Canada found a lack of integration of evidence, collaboration in planning and service delivery, and evaluation of services for youth (Anderson & Lowen, 2010). Many smaller, remote Indigenous communities have limited or no access to mental health services, and lack appropriate and engaging services (Boksa, Joobar & Kirmayer, 2015; Malla et al., 2016).

There is evidence that several countries are now engaged in transformation of youth mental health services and in evaluation of these initiatives (Malla et al, 2016; Patton et al, 2016). In the Canadian context, the salient trend is towards Integrated Youth Services (IYS). Halsall et al. (2019) describe the IYS model as bringing together a range of services used by young people — including primary care, mental health, addictions, vocational, and other social services — under a commitment to holistic and client-centred care. This orientation requires contextual attention: approaches to IYS may differ and be informed by different actors in every setting. The meaningful engagement of youth and families and the incorporation of perspectives from diverse populations represented within the community have been deemed essential to the implementation of IYS, while more description, research and evaluation of the model and its constituents is needed (Halsall et al., 2019; Salt, Parker, Ramage & Scott, 2017).

Urgency: the rising impetus for youth engagement.

The shift in the philosophy and orientation of service delivery exemplified in the IYS model posits the perspectives of young people as a fundamental element for change. Youths' input in service design and evaluation is now seen as a requirement if care is to be developmentally informed, contextually relevant, and engaging (Pullmann et al., 2013). This call for inclusion of their knowledge is a consistent message from scholars in the area, as well as in national and provincial strategies for systems change (Iyer et al., 2015; Malla et al., 2016; Mental Health Commission of Canada, 2012; Mulvale & Bartram, 2009; Ontario Ministry of Health and Longterm Care, 2011; Youth Wellness Hubs Ontario, 2017). Government funding applications for youth mental health design in Canada specify youth and family caregiver engagement as a criterion for funding success (Youth Wellness Hubs Ontario, 2017).

The rationale for youth engagement broadly is that it makes possible accurate representation of young people's unique needs. This ideal is now espoused in diverse forms by every policy and mental health service-design initiative targeting youth in the country. Youth engagement has also begun to feature prominently in other policy areas, such as climate change, human rights-based approaches and Reconciliation with Indigenous peoples in Canada, as symbolized by the ongoing engagement of a Prime Minister's Youth Advisory Council at federal level (Government of Canada, 2019). In popular and historical spheres, youth voices

have made significant inroads in recent years, harnessing technology and collective strength to combine engagement, activism and political action. Adults and institutions in diverse settings have interacted with youths' way of knowing, to different effects: Taksim Square in Turkey (Kuymulu, 2013), the contemporary Sudan region (Hale & Kadoda, 2014), the DREAMers movement (Nicholls, 2014), and the theatre of gun-control legislation in the United States (The Guardian, March 24, 2018). In all of these circumstances, I note the large gulf between young people taking or being given a space to share what they know, and the realization of change based upon their needs.

Defining youth engagement as a single, monolithic construct proved a challenge. A review of the literature uncovered that there is no single agreed-upon definition or understanding as to what youth engagement entails. Indeed, theoretical and empirical work on YE reveals that it can occur under diverse agendas with varied goals. These goals may include the impetus to increase self-efficacy and capacity in youth (Checkoway, 2011; Foster-Fishman, Law, Litchy & Anoun, 2010; Rodriguez & Brown, 2009), the aim of fostering trust and youth-friendly services, improving accountability for quality care (Ambresin, Bennett, Patton, Sancu, & Sawyer, 2013; Kutcher & McLuckie, 2013), or the commitment to develop and implement a mental health strategy in collaboration with those it is geared to serve (Mental Health Commission of Canada Youth Council, 2015; Mental Health Commission of Canada, 2016). Similarly, operationalization of engagement is diverse and highly contextual: a recent systematic review of frameworks for patient and public involvement suggests the limited transferability of engagement efforts (Greenhalgh et al., 2019). This heterogeneity in rationale and operationalization of YE will be discussed in Chapter 2.

As it pertains to youth engagement in service design, it suffices to note in this introduction that, in spite of the fervour for engagement exhibited in national and global strategies for service reform, the available evidence is unclear on the degree and manner to which youth engagement meaningfully informs policy or improvement projects. Calls for evaluation abound (Lincoln, Borg & Delman, 2015). Evaluation of YE initiatives has primarily focused on the individual outcomes for the youth engaged, reporting on individual increases in capacity and self-efficacy, and the development of coping and professional skills (Monson & Thurley, 2011). Youth engagement is least developed with respect to the articulation of

outcomes at the organizational and system level. The challenge of evaluating organizational outcomes remains limited by the diversity of contexts undertaking youth engagement values, and the scarcity or low application of theoretical models to inform research and evaluation.

Envisioning youth engagement as transformative.

This project responds to a need for the re-evaluation of the potential for, and application of, youth engagement in the design of appropriate services for youth mental health. In the initial stages of this study, I conceptualized the term as an element of mental health system transformation efforts. In doing so, I qualified engagement itself as ‘transformative’ because it is fundamentally intended to lead to change. This expectation of engagement, that it be transformative, informed the questions and conditions examined in this inquiry.

Research Context: ACCESS Open Minds

I set out to examine how youth engagement happens at the organizational level, seeking to reveal its best practices, barriers and everyday reality. The context for this inquiry was a single service site within ACCESS Open Minds, a multi-disciplinary, national research project of system transformation.

ACCESS Open Minds is formally titled *Developing, Implementing and Evaluating a Model for Youth Mental Health Service Transformation: ACCESS – Canada*. ACCESS is an acronym that stands for Adolescent/young adult Connections to Community-driven, Early, Strengths-based and Stigma-free services. ACCESS Open Minds has involved a five-year mental-health system process of organizational and network change in six provinces and one territory in Canada.

What follows is a contextual description of the principles and objectives of the national ACCESS Open Minds project, which in turn determines many characteristics of the particular research site where I studied youth engagement. The purpose of this detailed description is to set out the intentions of ACCESS Open Minds — both in terms of how youths’ knowledge is regarded as an input into system design, and in terms of how youth engagement is made reality within a practice context.

ACCESS Open Minds was launched in 2014 as a product of the Transformational Research in Adolescent Mental Health (TRAM), in itself the first of the Strategy for Patient-Oriented Research (SPOR) programs of the Canadian Institutes of Health Research (CIHR). TRAM was a collaboration of the CIHR and the Graham Boeckh Foundation. Their combined \$25 million commitment represented the first time such a public and private funding effort had been dedicated to youth mental health service transformation. The relationship between ACCESS Open Minds and youth engagement originates in this collaboration by the Graham Boeckh Foundation and the SPOR program.

The Graham Boeckh Foundation traces its origins and purpose to the death of 22-year-old Graham Boeckh, the result of complications from medication to treat schizophrenia. The Foundation is grounded in the belief that “the health system failed Graham, as it has countless others, through poor access, misdiagnoses and improper care and supervision” (“About Us”, 2016). The Foundation acts as a catalyst for transforming mental health services nationally and internationally, by supporting and initiating projects that aim to break down siloed approaches within the mental health sector, and that place patients and families at the centre of care. Its support of youth mental health in Canada has included further development of Integrated Youth Services, including Youth Wellness Hubs Ontario, Foundry in British Columbia, and FRAYME, a knowledge-transfer network designed to connect and accelerate IYS initiatives across Canada and internationally.

As noted, ACCESS Open Minds is also supported by CIHR’s Strategy for Patient Oriented Research (SPOR). SPOR refers to a continuum of research that engages patients as partners, focusing on patient-identified priorities with the goal of improving patient outcomes (Canadian Institutes of Health Research, 2014). CIHR SPOR Patient Engagement, 2014). Research projects funded under SPOR principles feature multidisciplinary teams in partnership with relevant stakeholders, with the intention of applying the knowledge generated towards systems improvement. A primary objective of SPOR initiatives is to foster evidence-informed care.

The approach of ACCESS Open Minds has been to target, at the level of community service in its 14 network sites, all mental health problems at all levels of severity in youth, ages 12 to 25, with special attention to populations at high risk, such as youth who are homeless or

living in Indigenous communities. The goal is to implement, evaluate and elaborate a transformation in the way youth access and use mental health services in real-world settings. Site-specific transformation plans vary according to the needs of the context, but include early-case identification, rapid access, appropriate care and continuity of care beyond the age 18 transition. Through the course of its five years, ACCESS OM has also been leading the development of a national standardized evaluation framework for integrated youth services with other partners in the country, including FRAYME, Foundry BC, and Youth Wellness Hubs Ontario.

Engagement is both a founding pillar, and one of the objectives of the project. This conceptualization means that engagement both guides at the level of values, and is considered an outcome of activities. Through its own design and development, ACCESS Open Minds has included the significant input of youth and family stakeholder groups, from the conceptualization of the vision of the project and its core values, to the implementation and evaluation of the service transformation at each site. Project governance includes national youth and family/caregiver councils that function in partnership with working groups in the project. Family and youth councils also exist at many of the 14 sites nationally, with different configurations of engagement in those sites which do not maintain a council model. A valuing of youth perspectives lies at the core of the project's activities, on the premise that "not only do youth have important insight into their own care, they are valuable partners in creating a vision of how mental health care can be in the future" (ACCESS OM Project Overview, 2017). Engagement is both a founding pillar, and one of the objectives of the project. This conceptualization means that engagement both guides at the level of values, and is considered an outcome of activities. The specific engagement of youth as stakeholders, according to the National project's lens, occurs at various levels:

1. As advisors to the national project, informing the project network at the macro level and shaping network activities and plans;
2. As site-specific advisors to address contextual care challenges at the site level, informing site plans and operations;
3. As individual stakeholders in their own care, engaged in their own plan of service

The Chatham-Kent Health Alliance.

I focused on the second level of engagement noted above, as observed at one site in operation within the ACCESS Open Minds network, ACCESS Open Minds Chatham-Kent. The Chatham-Kent site is the only ACCESS Open Minds site in Ontario. It serves a small, urban centre and the surrounding rural areas, for a total population of approximately 108,000, including two First Nations communities. Implementation of its ACCESS Open Minds transformation was launched publicly in May of 2016. Leading to the launch, and proceeding from it, ACCESS Open Minds Chatham-Kent held continuous consultation with family and youth groups, resulting in the creation of a Youth Advisory Council (YAC). The process of transformation at this service site was organized around working groups, as follows:

The Youth Advisory Committee (YAC) at the CKHA is composed of 16 youth and one adult Youth Advisory Board coordinator, who is also a social worker within CKHA ACCESS Open Minds;

The Operational Planning Working Group is composed of five YAC representatives and eight adult CKHA ACCESS Open Minds team and community-at-large members, including representatives from the local school board, the mental-health nurse for that board;

The CKHA ACCESS Open Minds Leadership Team is composed of 12 CKHA adult professionals, members of the local community and family council, and three YAC members.

Through the course of this research, the service site in Chatham-Kent underwent two notable, almost simultaneous developments. Its permanent youth hub space opened in August of 2018, realizing the youth-friendly space that youth and family advisors designed and contributed to through the early engagement processes at the site. Second, the site was named one of ten Youth Wellness Hubs Ontario (YWHO), an initiative funded by the Ministry of Health and Long-Term Care that aims to sustain the Integrated Youth Services model in the province.

Theoretical Constructs

The most important theoretical construct that informs this dissertation is engagement itself. In the chapters that follow, I will discuss the meaning and implications of engagement as in

relation to the scholarly literature, on-the-ground data, and discourse analysis that constitute this study. That process was itself anchored by other terms and constructs, as described in the remainder of this chapter.

Discourses shaping the mental health of youth.

I draw on the tradition of Critical Discourse Analysis (Fairclough, 1992, 2001) whereby discourse is defined as a “set of social practices that involves meaning making” (in Rudman, 2013, p. 170). Fairclough (1992) further explains that discourse is commonly used in various senses including: a) meaning-making as an element of the social process; b) the language associated with a particular social field or practice (for example, the ‘mental health discourse’); and, c) a way of construing aspects of the world associated with a particular social perspective (for example, the ‘neo-liberal discourse of public health management’). The aim of framing the discourse surrounding YE is to explore the connection between language and social institutional practices, and to wider political and social structures, with an interest in demystifying ideologies and power.

In IE, the stance taken towards any form of discourse is to question and *unsettle* the way that it can suspend or subsume experiential knowledge (Campbell et al., 2006). The social coordination that discourses perform consists of shaping how things are understood and carried out within particular everyday contexts. Smith (2006) explains the nature of this coordination in describing that any type of institutional discourse “sets up a way of seeing in terms of specialized functions”, with the upshot that people “aren’t as they are in actuality, but are expressions of pre-given categories: doctor, patient, nurse, pharmacist and so on” (p. 8). Following Fairclough (1985) and in keeping with similar assumptions in IE, I approached discourse in this investigation as a constructive/coordinating ideological frame with the capacity to underpin both daily activities and what is normal and right, even when the people involved in such processes are unaware of such coordination.

Knowledge.

An important assumption in this project is that it matters which forms of knowledge are taken up by the system. Knowledge in mental healthcare involves conceptualizations of mental

health, mental illness and its various biological and social determinants, as well as approaches to treatment, recovery or management of mental illness.

Various scholars have theorized about information and knowledge in ways that may illuminate the process of stakeholder engagement. Devlin (1999) described knowledge as “information that a person possesses in a form in which allows immediate use” (p. 2). Nonaka and Takeuchi (1995) make a similar distinction between information and knowledge, whereby information is a necessary medium or material for eliciting and constructing knowledge. Knowledge, they argue, unlike information, is about beliefs and commitments, as well as about action and meaning (p. 58). This distinction, and the process suggested between one and the other, calls attention to a context that holds values, pressures and dynamics.

Bowker and Star (1999, 1996), in their work focusing on large information systems and the classifications they uphold, note the politicized, contested nature of knowledge contexts. In the process of examining a particular infrastructure or knowledge system, they invite us to look for ways in which the values of the organization and the professional credo of its workers will give primacy to certain kinds of information over others. Further, Bowker and Star (1999) note that large information systems carry with them a “politics of voice and value which is often invisible, embedded in layers of infrastructure” (p. 33).

The act of selecting and structuring the information put to use in itself sets agendas and system priorities, shaping the nature of care and, consequently, its effectiveness. For example, in the knowledge context of mental health services, a fundamental site of knowledge adoption that shapes the direction of care has been the definition of mental health and mental illness. For some time now, scholars and practitioners in mental healthcare have pointed to the limiting consequences of a deficit-based model of care (Keyes, 2006; Slade et al., 2014). Malla, Joober and Garcia (2015) have noted the need to “examine the clinical and public utility of presenting a dominant neurobiological model of mental illness to patients, their families and the public at large” (p. 147). They, along with other scholars, underscore the role of societal values and social determinants of health upon youths’ development and life course wellness (Waddell, Shepherd, Chen, & Boyle, 2013). Additionally, there is large body of evidence on the strong link between the protection of basic civil, political, economic, social, and cultural rights of people and their mental health (World Health Organization,

2005). In processes of engaging populations who have been traditionally marginalized as knowers, the nature of barriers and supports for the uptake of information exceeds interpersonal dynamics and is embedded in institutional and structural relations that shape the context of engagement.

Epistemic justice.

A final theoretical area that has been instrumental in the conceptualization of this project stems from the writings of Fricker (2007) and Medina (2012), both of whom work from a perspective of social epistemology, ethics, and social and political philosophy.

In her book, *Epistemic Injustice: Power and the Ethics of Knowing* (2007), Fricker proposed the concepts of epistemic justice/injustice to address the treatment of previously excluded populations in their capacity as knowers. She focused on processes by which people lack or gain access to, and participation in, knowledge practices, which include accessing, holding, creating and sharing knowledge. Fricker theorized two forms of epistemic injustice: 1) testimonial injustice, in which someone is “wronged in their capacity as a giver of knowledge” (p. 7); and 2) hermeneutical injustice, in which someone is wronged “in their capacity as a subject of social understanding” (p.12). The hermeneutic level refers to a person’s access to resources that allow them to understand a context or narrative. This dimension of epistemic justice is relevant to discussions of youth engagement because mental-health system knowledge has traditionally been within the purview of experts, and so it is not surprising that youth may not understand what occurs in the decision-making of that context. The testimonial level refers to whether a person’s way of knowing is considered credible or given value in society. Testimonial injustice is caused by prejudice against the credibility of specific populations.

Other scholars have taken up Fricker’s concepts and focused on their specific dimensions. Medina (2012) advanced Fricker’s conceptualization with a detailed analysis of the way forms of epistemic injustice are perpetuated in subtle ways, with far-reaching consequences. Origi (2012) and Maitra (2010) discussed mechanisms that bias the credibility assessments a hearer makes upon hearing a particular population’s testimony, with consequent testimonial justice or injustice. In a discussion of testimonial injustices that result from systematic identity prejudices, Maitra (2010) qualifies testimonial injustice as occurring when speakers

suffer credibility deficits due to identity prejudices on the part of their hearers. Maitra goes on to describe that an identity prejudice is systematic (rather than incidental) when it tracks the individuals it targets across several aspects of their lives – economic, educational, professional, sexual, and so on (p. 27). According to Fricker, the central cases of testimonial injustice are cases of identity injustice in which hearers rely on stereotypes to assess the credibility of their interlocutors. Her definition of identity prejudice is “a widely held disparaging association between a social group and one or more attributes, where this association embodies a generalization that displays some ... resistance to counter-evidence (Fricker, 2007, p. 35). Key in understanding the impact of such prejudices in the occurrence of epistemic injustice is the acknowledgment that these prejudicial stereotypes can “come in positive or negative form” (Maitra, 2010, p. 27).

In the context of mental health services and research, specific forms of knowing have enjoyed long-standing and often unquestioned credibility and dominance. As such, the structures of understanding that shape mental healthcare may favour professionals, so that they both hold hermeneutic resources and credibility in disproportionate amounts compared to service users. Lakeman (2010), reflecting on professional culture in mental health, posited that actual and potential testimonial injustice has long been endemic within mental health service delivery. He argued that central to mental health legislation is the idea that some people lack the capacity to make decisions; it follows, he said, that “what they might say, how they construe problems, their choices and preferences lack coherence, logic or credibility” (p. 151). Lee et al. (2019) extended this line of thinking in an exploration of clinical social work, finding that service providers claim disciplinary power to make the care moment more efficient, tractable and treatable, with the effect of managing the client.

Carel and Kidd (2014) undertook a philosophical analysis of the concept of epistemic injustice in healthcare, arguing that ill persons are particularly vulnerable to epistemic injustice at both the testimonial injustice and hermeneutical injustice levels. They describe that ill persons “are vulnerable to testimonial injustice through the presumptive attribution of characteristics like cognitive unreliability and emotional instability that downgrade the credibility of their testimonies” (p. 529). As well, ill persons are also vulnerable to hermeneutical injustice because many aspects of the experience of illness are difficult to

understand and communicate and this often owes to gaps in collective hermeneutical resources. Consistent with Lakeman (2010) and Lee et al. (2019), Carel and Kidd characterize these injustices as, in part, owing to the epistemic privilege enjoyed by the practitioners and institutions of contemporary healthcare services. This privilege, they argue, is in itself related to training, expertise, and certain styles of articulating and evidencing testimonies in ways that marginalize ill persons. The upshot of these injustices is patients' persistent experiences of being epistemically marginalized or excluded by health professionals; these are plentiful in the literature in healthcare and mental healthcare (Fierlbeck, 2011; Franke, 2010; Leblanc & Kinsella, 2016). This is the context where youths' perspectives are invited in processes of engagement.

As applicable to this research, the concept of hermeneutical injustice also begins to reveal the position that adult service providers might experience: adults may have difficulty making sense of youths' experiences in part because youth themselves have not yet developed the resources of understanding needed to express and make sense of their experiences.

Employing the concept of hermeneutical injustice when examining engagement avoids the oversimplification of adults as dismissive of youths' experiences, and sheds light on the challenges of youth-adult engagement as the outcome of a long-standing exclusion. The potential for youths' knowledge to be considered a legitimate input into system design is not hindered merely by youth-adult dynamics now, but by a long precedent of youths' absence from conversations that would have ensured their capacity to understand and interpret their own views on the subject of mental healthcare. That is, in a context predetermined by other forms of knowledge (biomedical, clinical, etc.), the youth 'subject' cannot make proper sense of their healthcare needs, owing to the fact that youth as such have been excluded from making a contribution to the collective resources for social meaning or understanding of appropriate care.

An additional consideration when reflecting on the construct of epistemic justice has been the contributions of Intersectionality (Crenshaw, 1991; Shields, 2008). This work was undertaken in consideration that youth and service providers all inhabit multiple identity categories and social locations. How they are perceived as knowers, and how they are responded to by their social and professional environment is affected in turn by the multiple

positions, including the simultaneous privileges and forms of oppression that they experience.

Neoliberalism and new public health management.

I draw on Spence (2016) in referring to neoliberalism as the general idea that society works best when the people and the institutions within it are shaped to work according to market principles. A central characteristic of a neoliberal agenda and the governmental processes that promote it is the pressure for people to operate as responsible, self-reliant and self-regulating individuals (Dean 1995; Kennelly, 2011), and as viable consumers of products and services (Brown, 2006; Esposito & Perez, 2018). Under the stress on individual responsibility, populations who are dependent on support from the social state become the targets of a discourse that fosters self-improvement, self-commodification, self-reliance and engagement in economically useful activity (Rudman, 2006; Walters 1997). The individualization of the problems implicit in policies that eliminate services to these populations serves to absolve governments from the responsibility for addressing issues (Huot, Bobadilla, Bailliard, & Rudman, 2016).

As a governmental technology of neoliberalism, new public health management is linked with the decline of the welfare state. Its healthcare reforms are characterized by an accounting logic of tracktable outcomes as the only rationale for the sustainability of programs, and by the responsabilization of individuals through an emphasis on professionalized expertise and forms of knowing. As structural factors beyond an individual's immediate control and environment fall from view, concerns of health, mental health and health services become framed by the illusion of choice, and a consumerist approach to understanding wellbeing (Esposito & Perez, 2018; Gerlach, Teachman, Laliberte-Rudman, Aldrich, & Huot, 2018).

Chapter development.

I will develop this dissertation through the following five chapters. In Chapter 2, I will describe the scholarly literature attending youth engagement efforts, in order to understand whether and how concerns of epistemic inclusion and exclusion have been made explicit. In Chapter 3, I will set out the methodological approach for this study. In Chapters 4 and 5, I

will detail findings derived from interviews and meeting observations (Chapter 4), and from a discourse analysis conducted in the practice texts that inform YE efforts at the local site (Chapter 5). Finally, in Chapter 6, I will discuss findings, as well as study implications and limitations, outlining future areas for research and concluding this dissertation.

Chapter 2

Chapter 2: Scholarly Context: Youth Engagement

The current scholarly understanding of youth engagement (YE) in Canadian mental health services research has pluralistic roots, and a still-shifting, amorphous conceptual base. Many disciplines and orientations inform YE in this area. Influences include: the methodology of Participatory research and its associated approaches; the program-development approach of positive youth and community development, often influenced by the discipline of community psychology; and the social movement of patient/service-user/consumer participation and involvement. Many of these approaches are themselves influenced by other revisionary moments as to whose knowledge counts in relation to questions of health, mental health, and the position of youth as knowers. The Recovery movement (Charlton, 1998), Disability Rights (Shakespeare, 2013) and anti-psychiatry (Crossley, 1998) have contributed to the current *why* and *how* of YE. To consider all these areas of provenance means to approach youth engagement with simultaneous faith in its promise, and a healthy skepticism¹ regarding shortcomings in definitional coherence, practical know-how and clarity of evaluation.

In this chapter, I will review the scholarly literature to describe the four distinct ‘disciplinary’ narratives that inform current engagement initiatives in mental health services research and practice. Scholars from these vantage points employ several distinct but interrelated terms — such as participation, partnership, engagement, involvement, and co-creation — to signify their activities. The object of this review has been to trace the development of YE in relation to the theoretical concerns of this study. As such, this review is bounded by a concern on how knowledge and structural concerns are treated, in theory and practice, by each of these approaches. I did not strive to comprehend the full motivations for engagement, or the resulting empirical evidence, from each disciplinary area of engagement. Instead, I describe each discipline’s treatment of YE in terms of its definitional coherence, underlying values,

¹ A short note on my own skepticism is merited here. This review of YE and most, if not all, of the scholarly literature examined, is underpinned by Westernized assumptions of what it means to be a young person, and an adult in relation to young people. I am grateful to Dr. Iyer, who reminds me that we don’t know enough about why and how YE could proceed in contexts where youth are also seen developmentally as inter-dependent (e.g. needing and benefiting from wisdom and experiences of older people, and where this inter-dependence is highly valued). Other disciplinary areas may be contributing to this dimension of YE, and represent important knowledge to be sought as complement to the present study.

attention to individual and structural dynamics, and knowledge concerns. I will then describe, in a subsequent section, recent developments in the conceptualization and application of YE to mental health services design.

Participatory Research

Participatory research in all of its forms — including Participatory Action Research (PAR), Youth-centred Participatory Action Research (Y-PAR) and Community-Based Participatory Research (CBPR) — is a methodology that has its roots in critical and liberation psychology, with key contributions from two originating traditions (Cornwall & Jewkes, 1995; Healy, 2001). The Northern tradition of PAR was initially developed by Kurt Lewin (1946), in the fields of Social Science and Psychology. Its theoretical underpinnings include the democratic tradition of collaborative, action research, promoting social equality and empowerment where people for whom the change is intended are at the core of decision-making with equitable roles in the research process. Credit is given to Lewin for coining the term ‘action research’ to link the cycles of theory, practice, and problem-solving (Burgess, 2003; Minkler & Wallerstein, 2003).

The Freireian, or Southern tradition of participatory research, evolved from the community-development, action and liberation-pedagogy principles of Paulo Freire (Freire, 1970, revised 1993). It is rooted in the Marxist tradition of emancipatory research, with a focus on giving voice to marginalized and disempowered individuals, communities and groups. Freire advanced the concepts of critical consciousness (conscientization) and social action (praxis) in relation to the collective power gained by oppressed Latin American communities. The processes of PAR in this tradition centre on dialogical education principles, whereby the dynamic relationship is between the student and the teacher. The principle of mutuality constitutes the core of this dynamic: the empowering teacher not only teaches, but also learns; the students, in being taught, also teach (Freire 2000). The goal of this process is liberation from oppressive regimes through the emancipatory creation and transmission of knowledge.

The values of participatory research.

Increasingly, the rationale for PAR in relation to health, particularly in its community-based participatory research branch, has more explicitly been connected to the rights-based orientation underpinning a health equity agenda. Efforts to engage and create knowledge with populations who have experienced marginalization help to address health inequities in two ways: first, they increase the evidentiary base about the particular health and social conditions of populations, particularly those who have been excluded from research and policy; second, when such evidence is applied, PAR increases equitable access to health services systems by supporting the creation of programs and policies that are appropriate and tailored for the needs of such distinct groups (Israel et al., 2010; Israel et al., 2019; Wallerstein & Duran, 2010).

To achieve this goal, participatory approaches to research are guided by values that must be adapted according to the context of application. Together, all participatory approaches have been described as valuing community collaboration and cooperation, equitable partnerships, empowerment, participation, and a dialectical/dynamic process that involves systems development and building on the strengths of partners (Cornwall, 1995; Kirk, 2007; Maiter, Joseph, Shan & Saeid, 2013). Proponents of PAR in YE align with the aims of critical research, and thus seek to expand awareness that social challenges are situated beyond individuals and lie also in processes and social institutions that act on youth (Camarota & Fine, 2008). As such, the value system of PAR and Y-PAR falls under the ethics of social justice, and Y-PAR work is explicitly political.

As noted by Cornwall and Jewkes (1995) early in the development of the methodology, “participatory research raises personal, professional and political challenges which go beyond the bounds of the production of information” (p. 1667). It is a hallmark of this research approach to reflect on and problematize the notion of participation, and to strive to express and analyse the dilemmas inherent in the process of engagement. Perhaps because of this methodological commitment to self-reflexivity, Y-PAR scholars are notable for their attention to power differentials between youth and adults, particularly as these emerge in the process of youth engagement activities. Berman and Jiwani (2014) described the need for reflexivity and attention to power dynamics between youth and adults through the various

stages of research, particularly as it relates to institutional hierarchies that, visibly or invisibly, impact collaboration among academic, community, and youth co-researchers.

For Y-PAR to be enacted according to its values, particular characteristics and practices on the part of the adults involved are essential, in addition to being self-reflexive. The relational dimension of PAR has been examined in studies involving various pairings, such as students and teachers, and adult researchers and youth co-researchers (Schon, 1998; Mooney, 2005; Rodriguez & Brown, 2009; Stoudt, Fox & Fine, 2012). Scholars exploring this have underscored, for example, the need for adult researchers to relinquish the role of sole experts in the creation of knowledge (Rodriguez & Brown, 2009; Kemmis, McTaggart, & Nixon, 2013); the different types of relative privilege that are constantly operating in youth-adult partnerships (Stoudt, Fox & Fine, 2012); and the dangers of reifying essentialist and problematic dominant assumptions about youth (Berman & Jiwani, 2014; Fox, 2013; Kirshner, 2008). Additional considerations in the enactment of PAR values have been explored by self-reflexive researchers who, though not focused necessarily on youth, have sought to unpack the potential for regulation (Beresford, 2002), tokenism (Kesby, 2007), ventriloquism (Sexton & Sen, 2018) and co-optation (Cahill, 2007; Cooke & Kothari, 2001).

Structural and knowledge concerns.

Beyond attending to interpersonal power differentials, examining how issues of power affect an individual's relationship to institutions is a fundamental practice in Y-PAR that is true to its values. This area has been most consistently developed by researchers in the areas of education, social sciences and community health (Cammarota & Fine, 2010; Fricker, 2008; Israel et al., 2019). Genuine engagement, in the language of PAR, is directly connected to critical reflexivity, collective responsibility, and solidarity (Caraballo, Lozenski, Lyiscott, & Morell, 2017; Fox, 2013).

Despite its focus on relational dynamics between youth and adults, Y-PAR engages directly with structures and institutions of power through its attention to democratizing knowledge production. A core objective and value of any Y-PAR process is to foreground and validate local knowledge, as well as, in the case of youth participation, their authority to determine "truth" (Kesby, 2005). Rodriguez and Brown (2009) discuss Y-PAR as a means to shift the role of marginalized youth "from simply giving voice, to becoming change agents on the

conditions of their lives” (p. 19). Foundational to this shift is a recognition of mutual contributions, between youth and adults, in the exchange and creation of knowledge.

In seeking to generate knowledge rooted in the everyday realities of youth, researchers employing Y-PAR undertake a commitment to “embrace complex, non-linear ways of knowing that reflect the ways marginalized youth speak to their own experiences” (Cameron, Murray, McAdam, & Suleman 2014, p. 234). These forms of knowing may face resistance at two levels: first, in their creation, because it takes effort to support persons who have not developed their role as knowers in articulating their experiences, as the characterization of consciousness-raising as a *process* suggests (Freire, 1970). Herein lies one aspect of the work in part, best articulated by Schon: “the teacher who is reflective and communicative can transform the student’s tacit knowledge into something explicit” (Schon, 1988, in Mooney 2005, p. 242). Writing from a social-sciences perspective, Cahill (2007) reflects on collective processes of making knowledge, describing the rituals and practices needed for sharing power within the research process, the role of facilitator, and techniques of collective data analysis. Developing this idea, Nastasi (2012) positions the knowledge-generating aspects of Y-PAR as a process of building resources of understanding among populations who have not had access to such resources.

The second area of knowledge work in PAR relates to the transmission of such knowledge into structures and audiences beyond the spaces of research. The outputs from PAR activities often stand in contrast to the way knowledge is created and articulated in contexts dominated by positivist and post-positivist research paradigms (including healthcare), and in academic publications that focus on youth from other research paradigms. Caraballo, Lozenski, and Morrel (2017) state “knowledges from academic and professional research-based institutions have long been valued over the organic intellectualism of those who are most affected by educational and social inequities” (p. 311). Y-PAR researchers challenge that continuously. Alongside Cahill (2007), Cammarota and Fine (2008), Fox (2013), and Berman and Jiwani (2014) have developed thoughtful discussions on the fine line between tokenistic engagement of young people, and processes that undertake complex knowledge and power exchanges, often mutual, and that lead to genuine exchange.

The consensus among Y-PAR scholars is that conveying such gains from Y-PAR is in itself a political enterprise that challenges and democratizes the production of knowledge. Many participatory researchers underscore the inherent tensions between PAR and academic processes of knowledge generation (Dentith, Measor, & O'Malley, 2012). Fox (2013) states that the practices required to achieve success in research “are often depowering for the people we are working with” (p. 997). She notes that the different ways of conceptualising knowledge construction by young people for young people may involve far less recognition for academia, adult-led organisations and researchers employed within them.

Y-PAR is fundamentally concerned with the role of youth as knowers. Fine asserts that PAR is “a radical epistemological challenge to the traditions of social science, most critically on the topic of where knowledge resides” (2008, p. 215). It is not surprising, then, that participatory approaches are used by child rights advocates, critical educators, community organizers and youth workers, many of whom have focused on problems of educational and health inequities, media portrayals, and discrimination based on sex, race, and class (Cammarota & Fine, eds., 2010; Caraballo, Lozenski, Lyiscott, & Morell, 2017; Ginwright et al., 2006; Torre & Fine, 2006).

Implementing and evaluating participatory processes.

Participatory processes are often evaluated for their effectiveness as the developmental or process level, most often through qualitative and narrative accounts of the research process. Some scholars argue that values-application is still highly inconsistent in Y-PAR. For example, in a review of 399 community-based participatory research articles relating to children and youth, Jacquez, Vaughn and Wagner (2012) noted that researchers partnered with youth during some phase of the research process in only 15% of projects. Others have raised concerns that insufficient description of methods of analysis undermines the effectiveness this type of research (Foster-Fishman, Law, Lichty & Aoun, 2010). Others argue that the nuances of values-oriented partnerships are simply not translated effectively within the truncated descriptions demanded by academic journals (Flicker, 2008; Nastasi, 2012). An overarching concern suggested by all of these comments is whether the work of Y-PAR is fully developed and described in the context of academic, practice and policy discourses, timelines and expectations.

Another concern, articulated by Foster-Fishman and colleagues (2010), is that the action element is less effective than desired, suggesting a scarcity of uptake of the knowledge generated by youth through the participatory process. This highlights an important tension in Y-PAR, namely that the problems it seeks to examine and address exist in a large and complex systemic context. It is not realistic to expect wholesale change to result from a time-limited process of research. Scholars like Cahill (2007) have developed an understanding of the process-outcome relationship in Y-PAR, noting that “engaging young people in research helps challenge social exclusion, democratize the research process, and build the capacity of young people to analyze and transform their own lives and communities” (p. 298). While lamenting that not enough consideration has been given to evaluating the practice of doing research with young people, Cahill calls for “self-reflexive accounts of practice evaluating what works and what does not” (p. 299).

Reflecting on the barriers to effective participatory research in the context of medical institutions, Ahmed, Beck, Maurana, and Newton (2004) noted that the philosophical shift required by PAR is a major undertaking for an organization. New ways of thinking related to a participatory process include respecting the knowledge of communities, envisioning the organization as part of the surrounding community, and underscoring that improvements in the health of a community are more likely to occur if the community participates.

Recent developments in the conceptualization of Y-PAR support clarity and direction in the evaluation of its activities. In a review of Y-PAR as an equity-focused approach to promote adolescent health and wellbeing, Ozer (2017) proposes that Y-PAR be conceptualized at various levels:

- 1) At the social-ecological level of a young participant, [where] Y-PAR is an intervention intended to support positive youth development and psychological empowerment, with potential effects on the youth who become researchers;
- 2) As an intervention into the settings and systems that shape youth development (e.g., K-12 schools, after-school programs, health systems, and communities) that youth researchers study and seek to improve; and,

3) As an innovative approach to conducting scientific inquiry that engages youth as experts and co researchers, disrupting standard assumptions about who has expertise to create knowledge about young people. (p. 174)

Indeed, there are now various domains of evidence that show Y-PAR can be effective in meetings its aims to increase contextualized evidence in relation to distinct populations of youth. Robson, Ashbourne and de Leon (2016) reported on the effectiveness of Y-PAR combined with art-based methods to generate a contextualized understanding of how marginalization and homelessness impact youth wellbeing, including mental health. Maxwell (2017) used Y-PAR to articulate the experiences of young people in relation to rurality, gender-based violence, and access to supportive services.

Y-PAR has also been found effective in relation to positive individual outcomes for youth engaged in Y-PAR activities (Cammarota & Fine, 2008; Johnson, 2019, in press; Minkler & Wallerstein, 2011). In the areas of Education and Community Development, various researchers found effectiveness in increasing individual self-efficacy and capacity in youth; this remains an enduring rationale for their involvement in research and community-development initiatives (Checkoway, 2010; Foster-Fishman et al., 2010; Rodriguez & Brown, 2009). A second area of impacts relates collective benefits to the community or society at large. For example, knowledge generated from participatory approaches is considered to be more culturally relevant and connected to people's lived experiences, thus benefiting research, policy and programming activities (Jacquez et al., 2012; Soleimanpour, Brindis, Geierstanger, Kandawalla, & Kurlaender, 2008). Woodgate, Zurba, and Tennent (2018) argue that meaningful, rewarding engagement of youth and their families in health research includes a process of promoting identity, building capacity, and encouraging leadership skills. Woodgate and colleagues posit that such processes have an indirect impact upon the organization and, by extension, healthcare, thus addressing some of the long-term aspirations of Y-PAR.

Y-PAR in mental health services research.

Scholars who align with a participatory methodology argue for the importance of research that is directed by users/survivors, advocating for lay persons, including youth, to have a voice in planning and running services, and to stimulate choices and alternative forms of

treatment (Baum, MacDougall, & Smith, 2006). Various scholars have proposed stakeholder- and youth-directed research, and described mechanisms for the research-training of persons with lived experience of mental illness, including youth. For example, Lincoln, Borg and Delman (2015) developed and employed a CBPR model to investigate the engagement of Transition Age Youth (TAY) in service design. They found that that the guidance provided by CBPR principles could be applied in the development of the project, creation of the research team, training, the design and conduct of the study, leading to the creation of equitable partnerships and meaningful inclusion. Though the ability to observe values-implementation at the relational level is clear, Lincoln and colleagues lament the lack of robust evidence on exactly how youth engagement informs policy or improvement projects.

Other scholars have also advocated for the use of participatory approaches in mental health services research (MHSR). Jacquez, Vaugh, and Wagner (2013) underscored the need for young people to gain the necessary knowledge resources to participate meaningfully. Adolescents were trained as student researchers to identify the health needs of their peers and articulate strategies that improved the delivery of care in school-based health centres. Flicker and colleagues (2008) collaborated with 57 youth in community-based projects of health promotion using technology, and proposed a theoretical model for electronic-Participatory Action Research (e-PAR) as a result of their process. In Austria, Nitsch et al. (2012), in a literature review of stakeholder engagement in the participatory evaluation of health promotion activities, noted that while many of these projects were articulated under a PAR approach, the decision-making power seemed to be held predominantly by program staff.

The interest of Y-PAR in ensuring that the knowledge of lived experience can reach mental health systems of care has been explored by several authors (Smikowski et al., 2009; Soleimanpour et al., 2008). Participatory projects engaging youth have included research with young adults with psychiatric disabilities (Delman, 2012), young adults experiencing bipolar disorder (Noack et al., 2016), and in training young people with experiences of mental illness as research assistants (Lincoln, Borg & Delman, 2014).

Empirical accounts of Y-PAR in health services often offer limited information on its explicit social-justice orientation. Instead, Y-PAR and YE are employed instrumentally to improve services. What some researchers do make clear is that the attention to power underscoring

participatory processes, as well as their focus on relationship-building in the engagement of persons with lived experience of mental health challenges, holds great importance in health and mental-health contexts (Ochocka, Janzen & Nelson, 2002; Soleimanpour, Brindis, Geierstanger, Kandawalla, Kurlaender, 2008). Implicit in this shift is the assumption that the full range of user/survivor perspectives, as well as their competing conceptualizations and epistemologies of mental illness, merit a place in the research and academic discourse.

Positive Youth and Community Development

The fields of positive youth development (Hart, 1994, 2008; Lerner, Dowling, & Anderson, 2003; Lerner, 2005; Roth & Brooks-Gunn, 2003) and community youth development (Hughes & Curnan, 2000; Perkins, Borden, & Villarruel, 2001) have generated important knowledge on how to build programs that involve youth in engagement activities by moving from deficit-based models to more positive, developmentally focused approaches.

Rather than a methodology, positive youth development is a theoretical perspective, and investigators who adopt this perspective sometimes also employ participatory approaches in their research. This perspective is rooted in developmental psychology, and emphasizes that every young person has strengths and potential for healthy development (Lerner, 2002; Lerner, Phelps, Forman, & Bowers, 2009). Youth participation, youth empowerment, and positive-youth development activities all stem from this orientation. A key assumption by some authors in this field is that youth are disempowered from participation in society; the exploration of how this imbalance might be addressed is rooted in emancipatory concerns. Researchers in this area are explicit in their goals of improving youths' lives and development by creating conditions for youth to be agents of change (Ginwright & James, 2002; Checkoway, 2011). They employ youth engagement as a means to facilitate social change, to improve organizations, and to build healthier communities (Blanchet-Cohen, N., Linds, W., Mann-Feder, V., & Yuen, F., 2013; Checkoway, 2012).

The values of positive development research.

Positive development research aligns with PAR's processes of consciousness-raising, and is influenced by theories of sociopolitical development and empowerment (Kirshner & Ginwright, 2012; Zimmerman, 2011). Researchers in this area assume that young people

operate in a context of injustice and exclusion from the structures of society, and undertake research to support them analyzing the systemic factors that contribute to inequalities, as well as taking action to help address these factors (Ozer, 2017).

Youth participation became linked to the concept of children's rights through the emergence of the first typology of engagement, Hart's Ladder of Participation (Hart, 1994), which made possible more formal acknowledgements of young people as assets in decision-making processes (Shaw-Raudoy & McGregor, 2013). These principles received their first policy-level endorsement in the United Nation's Convention for the Rights of the Child, Article 12, which states that those under the age of 18 have the right to participate, to be heard legitimately, and to be part of the very decisions that affect their day-to-day lives (United Nations, 1989).

Structural and knowledge concerns.

An important contribution of this area of scholarship has been the development of theory and empirical evidence on the construct of Youth-Adult Partnerships (Y-APs). Such partnerships are rooted in the idea that mutually influential relations between the developing individual and the multiple levels of his or her context are intrinsic components of the basic processes of development (Lerner, 2002). In recognizing the potential for such mutuality, researchers in this area call for "a shift from conceptions that naturalize youth as 'deficient'" (Shaw-Raudoy & McGregor, 2013, p. 391). Y-APs are defined as "coaching, dialoguing, and connecting to institutional resources and community leaders" (Camino & Zeldin, 2002, p. 218). In exploring the nuances of partnerships between youth and adults in organizations, scholars in this area have brought to light dimensions of engagement that add to its theoretical coherence and potential for measurement. For example, positive youth development literature holds central the concept of mutually beneficial relationships among youth and the people and institutions in their social world (Lerner, 2005). More recently, Roach, Wureta, and Ross (2013) applied an ecological analysis to two case studies to explain the dilemmas and challenges faced when forging youth-adult partnerships. They demonstrate that young people adapt to adult-provided structures in circumstances where adults are not ready to work in emancipatory youth-adult partnerships and do not modify adult-centric work. Roach and colleagues advocate for structural change in organizations to foster

developmentally-appropriate youth roles, relationships and activities that have traditionally been exclusive to organizational leadership and governance.

A second area of theoretical and empirical growth in youth-development is the construct of youth organizing, which articulates its aims as more overtly political (Christens & Dolan, 2011). This has been an arena for youth development to concentrate on the conditions of youths' lives, addressing the systemic and structural dimensions of their daily experiences, including marginalizing structures that create and sustain exclusion (Watts & Guessous, 2006). Youth organizing centres on the intentional learning and application of strategies that enable youth to harness their collective social power and challenge structures of power to make community-level change (Pancer, Rose-Krasnor, Loiselle, 2002; Checkoway & Richards-Schuster, 2003, 2006). A tenet of the concept of youth organizing is to position young people, collectively, as experts in what matters to them. The ideal of youth organizing is for young people to choose issues that are important to them through a collective decision-making process, rather than working with issues that have been predetermined by adults or others (Christens & Kirshner, 2011; Speer, 2008). The role of adults is to support youth involved in organizing, but youth often take the lead in decision-making processes with respect to issue selection and strategies for achieving community-level change (Christens & Dolan, 2011).

Implementing the values of positive youth development research.

The goal of “meaningful” engagement, and the subsequent use of the qualifiers “meaningful” and “authentic” in other areas of YE policy and practice, stem from work in this area. Even with the focus of shared values and agendas of positive youth development and community development, there are multiple viewpoints and arguments regarding what “meaningful” means. For example, Shaw (2012) describes meaningful youth engagement as “the intentional establishment and support for the genuine involvement of young people in the design, creation, coordination, implementation, and evaluation of the processes, practices, and decisions that shape civic life” (p. 16). Shaw-Raudoy and McGregor (2013) in a study of 18 youth-engagement practitioners, researchers, and funders in Canada, found highly contextual and values-oriented definitions of ‘meaningful YE’, whereby it related to “the belief, value, and practice of putting youth at the centre” (p. 400).

Engagement with this orientation necessarily entails youth workers and educators enacting respectful and transformative youth-adult relationships, with the implication that such transformation is perceptible, and even measurable, at individual levels for those involved. Such ‘youth-adult partnerships’ (YAPs) function as instruments and catalysts to support meaningful participation. This conceptualization of meaningful engagement, and what adults can do in its pursuit, has prompted some researchers to challenge the nature of adult roles from experts to co-learners (Shaw-Raudoy & McGregor, 2013). This development is rooted in Camino’s (2000) assertion that the failure to consider mutuality, reciprocity and adult learning as central elements in youth engagement is limiting the field’s transformational capacity by entrenching the discussion in issues of power and empowerment.

The positive youth development literature has also contributed to a growing understanding of the contextual conditions for engagement. Some suggest that, in taking up the transformative agenda of youth and community development, youth and adults must collaboratively explore opportunities for extending YE beyond an individual project, to constitute a value system that underlies practice (Blanchet-Cohen, Linds, Mann-Feder & Yuen, 2013).

Empirical work in positive youth development has explored operationalization of YE in organizations and communities. Camino and Zeldin (2002) examined pathways for youth civic involvement, as well as facilitative policies and structures that larger institutions can employ within their established processes, to engage youth at the level of their interests and abilities. More recently, Campbell and Erstein (2012), using process and outcomes data from a multi-year initiative in seven communities, described beneficial results from YE at individual and community levels. These included “observable increases in the skills, confidence and leadership of individual youth; increased integration of vulnerable youth and families and their unique insights into schools and the broader community; increased capacity of adults to foster settings that allowed youth voice to mature; increased adult appreciation of the value of young people's ideas and contributions; and small but tangible steps toward community change” (p. 76). They also identified three critical implementation principles: (1) asking the right strategic questions in the right order; (2) creating organizational structures and processes that integrate youth and adults into joint decision

making; and (3) marshaling boundary-spanning community leaders with diverse skills and extensive networks.

Service-user involvement and participation

A third body of literature that relates to youth engagement is that of service-user involvement. This area has antecedents in ‘patient involvement’ and ‘consumer participation’ and extends over several decades and geographic points of origin.

For example, the term ‘patient involvement’ has a long history in the United Kingdom in the areas of healthcare planning, within and outside of the mental health field. The phrase ‘consumer participation’ appears also in the Australian mental health services policy discourse (Bennetts, Cross, & Bloomer, 2011; Stomski & Morrison, 2017; Tobin, Chen, & Leathley, 2002). In England, patient involvement has long been a subject of scholarly reflection. In 1992, Croft and Beresford examined the critical and political dimensions of patient involvement. Beresford (2002) traced the development of patient involvement in the context of British health services research. He examined mechanisms of participation, lamenting the episodic nature of the enthusiasm for participation, and the potential for co-optation and regulation of participatory techniques with the end of reifying institutional or structural agendas. Other scholars in this area, alongside Beresford, have deepened an understanding of said mechanisms, proposing that user involvement is about relationships in social contexts, and underscoring the need for user involvement early in the design of research and other activities (Smith et al., 2009).

All of the above terms have political implications, and denote a limited characterization of individuals: the term ‘patient’ is limited in that it frames individuals as ‘persons who are ill’ and waiting (patiently) to be acted upon, and thus treated/treatable by a biomedical approach. The term ‘consumer’ (or “customer, in some constructions) portrays persons as part of a transactional, market-oriented process involving their health and wellbeing. The terms ‘user’ and ‘service-user’ respond to these considerations (Beresford, 2007). A more recent approach to this question is the use of “patient/public” as a means to encompass these possible identities in relation to involvement and participation (Greenhalgh et al., 2019).

A further distinction when approaching this area of literature is the area of application. Involvement can be applied to research processes to generate knowledge, to service-design processes to impact the direction of programs and services, and those processes which combine both. The type of involvement distinctly not covered in this review relates individuals' involvement in their own care planning.

Under its many names, participation/involvement has its roots in an anti-oppression orientation; it has garnered theoretical and empirical momentum since the 1990s. The phrase “nothing about us without us” — which stems from the disability rights and recovery movement (Charlton, 1998) that informed patient involvement — has had long-reaching consequences in the current policy, advocacy and practice approaches to patient involvement and, by extension, YE.

As it relates service-design and reform, involvement has become increasingly connected to a health equity orientation. It is considered an essential element of service provision in mental health, and is defined as consumers participating in the planning of mental health services, service development and quality improvement (Tobin et al., 2002). Findlay (2000) and Lammers and Happell (2003) described that a key goal of these processes is facilitating change, in which users of services help transform the culture of mental health services, with the underlying assumption that change will lead to improvement. Developments in this area within adult services have shaped current interventions in youth services provision, with application in service planning, delivery and evaluation. Moonson and Thurley (2011) describe the adaptation of the participation model in the early intervention context, embracing values of flexibility, support and ‘consumer-centredness’.

In the area of research, Beresford (2007) described the instrumental role of involvement as a means to generate knowledge regarding: 1) health inequalities, namely remediable differences in health status relating to class, culture, gender, sexuality and ethnicity; and 2) differences in access to healthcare provision and health outcomes according to such differences. As such, involvement aligns with the principle of Participation, under the rights-based approach for health equity recommended by the World Health Organization's Commission for the Social Determinants of Health (2008) and adopted in the 2030 Agenda for Sustainable Development Goals.

In a systematic review of frameworks for patient/public involvement in health research, Greenhalgh and colleagues (2019) identified over 60 frameworks developed using both theoretical principles and extensive service-user involvement, noting that most of these published frameworks have been little used beyond the groups that developed them. This finding points to the highly-contextual nature of involvement practices.

Implementation of service user involvement.

A relevant practice element explored early on by this body of literature is the construct of the ‘consumer consultant’, namely employees in public mental health services who hold previous experience of service use, and who assist in the improvement of services through the inclusion of consumers’ perspectives across all aspects of service planning, delivery and evaluation (Bennett et al, 2011; McCann, Baird, Clark, & Lu, 2006). Many in this area regard consumer consultants’ perspectives as valuable to adult mental health services, and that such involvement offers individual and organizational benefits of such involvement (McCann et al., 2006). Important insights derived from this area are the identified barriers to the uptake of users’ knowledge into the system of care. McCann and colleagues, using a sample of 47 mental health professionals from two adult inpatient units in a hospital setting, identified that professional attitudes towards consumer representation was a difficult issue, and a hindrance to the uptake of consumer knowledge. Clinicians’ negative attitudes to whether consumer views would support, directly impact, or even impinge upon their roles.

Scholars in service-user involvement have accumulated empirical evidence of its effects, though youth as a distinct population are absent from most inquiries. There is general agreement, based on systematic reviews, that involving patients has contributed to changes in the design and provision of services across a range of different settings (Boivin, Lehoux, Lacombe, Burgers, & Grol, 2014; Crawford et al., 2002; Domecq et al., 2014; Simpson & House, 2002). There is also consensus that patient involvement is hard to evaluate: researchers note a lack of methods for engagement and a lack of understanding of its effects on use of services, quality of care, and patient satisfaction and health (Gillard, Simons, Turner, Lucock, & Edwards, 2012).

A notable advancement in the evaluation of involvement in service and system-level decision-making stems from the area of chronic disease management. Boivin and colleagues (2014) conducted a randomized controlled trial of patient involvement in six Canadian communities. The intervention tested was consultation with patients by writing and in person, versus a process of decision-making that only involved the professionals at each research site. These researchers found that patient consultation led to better priority alignment with a model of care that considered primary care, self-care support, patient participation in clinical decisions and partnership with community organizations. By contrast, priorities established by professionals alone placed more emphasis on the technical quality of single-disease management. Another notable finding was that patient involvement increased the costs of the prioritization process by 17%, and required 10% more time to reach consensus on common priorities. This study, though unrelated to mental healthcare, sheds useful insights on possible courses of action towards the evaluation of patient involvement in mental health service design, and validates the perception that patient engagement, though more costly and time consuming, makes a significant contribution to the design of care.

In 2014, Brett et al. conducted the first systematic review of patient and public involvement in health and social services research. Impacts identified included enhanced quality and appropriateness of research, through all stages of its process. In addition, this review identified some of the challenging impacts of user involvement, including, among others: a) scientific and ethical conflict in protocol design, which may have been due to a lack of knowledge and understanding of how to involve users, and included power struggles between researchers and users; b) challenges reported by researchers in running patient-involvement focus groups included users influencing each other, which may result in over-emphasizing particular problems; groups being dominated by strong characters and their perspectives; groups being overshadowed by personal experience stories, when the aim was to identify research topics; and, c) increased time and cost associated with user involvement led to increased time and cost owing to the practical aspects of planning and managing the actual engagement activities, the time and cost of building up relationships within the community and setting up user groups, the training and education for both users and researchers and the additional time needed for users to read and comment on documentation. The authors found evidence that the better the training, planning and definition of roles, the more positive the

attitude towards user involvement and the greater the trust and respect that parties (users, researchers, clinicians, funders, policy makers) had with each other, increasing the potential for benefit.

In a similar vein, in inquiries that examined the professional and organizational processes regarding service-user involvement in service design, researchers have noted the need for a shift in professional attitudes, as well as significant organizational commitments and clarity of direction (Gagliardi, Lemieux-Charles, Brown, Sullivan, & Goel, 2008), and organizational and practice barriers in the care context, within the organizations themselves (Luxford et al., 2011). Finally, Domecq et al. (2014) best describe the gaps in our knowledge about service-user engagement: 1) a lack of uniform reporting or indexing methods of engagement; 2) the unavailability of validated scales and the limited data reported in the studies; 3) the lack of standard tools for assessing the methodological quality of the studies.

Overall, the scholarly literature in this field features consistent calls for further research to demonstrate the value of patient engagement in service design to service leaders, organizations, researchers and funders, underscoring that there is much pressure to engage in the absence of know-how and evaluative expertise. The involvement of youth was not specified in these reviews.

Structural and knowledge concerns in patient involvement/consumer participation.

Existing scholarly developments in patient involvement, even if they do not focus explicitly on youth, have been useful to developing the present study because they examine the organizational and system contexts where engagement efforts occur. From their various contexts, these scholars provide a more nuanced understanding of how the realities of a health system setting interact with the values of involvement. For example, Walsh and Boyle (2009) examined how patient views alter the practice of healthcare, with a focus on user-led research involving patients in acute psychiatric hospital services. Bennetts and colleagues (2011) described the disconnect between the level at which consumers participate, and the organizational level at which the decisions are made; also, they noted gaps in the scholarly and organizational understanding of how managers in organizations perceive and operationalize participation. Others have focused on how to improve our understanding of

appropriate methods for involvement (Delman & Lincoln, 2009; Wallcraft, Schrank, Amering, 2009). Increasingly, commentators in this area have underscored that involvement is one instrument among many that contribute to quality healthcare in complex systems (Luxford, Safran & Delbanco, 2011; Luxford, 2012).

A further development in this area directly relating the role of lay persons as knowers has been the identification of user-led research as a distinct category from initiatives where users or patients are involved in research projects directed by someone else, often organizations or institutions. The former type of research is primarily concerned with bringing about change in line with the rights and wants of service users, putting the knowledge of people with experience as mental health service users/survivors at the forefront (Sweeney, Beresford, Faulkner, Nettle, & Rose, 2009). This development has been in response to arguments against involving patient views, including the belief that lay persons are too subjective to provide useful perspectives, or are unable to understand what quality care is (Litva et al., 2002; Luxford, 2012).

While much of the literature on patient involvement does not address youth as a distinct category, and fails to consider the implications of different developmental and cognitive factors in users' ability to participate, it does bring important insights and questions that translate to the involvement of youth as knowers in the design and delivery of care. Armstrong, Herbert, Aveling, Dixon-Woods, and Martin (2013) conducted ethnographic explorations of three different models of service-user engagement in quality improvement work in healthcare, outlining specific strategies that can be used to ensure that involvement works more effectively, and their enthusiasm for participation is maintained. These three models proved to be highly contextual, with service-users playing distinctive roles across the three different settings, acting as intermediaries between the wider community and clinicians, and sometimes doing persuasive and advocacy work to convince clinicians of the need for change.

Critiques of involvement merit consideration when translated to questions of youth engagement in mental health services. For example, an influential, and long-standing, critique suggests that patient involvement is often more about legitimizing managerial or professional decisions that would have been made anyway than about furthering patient

influence (Harrison & Mort, 1998; Peat, Entwistle, Hall, Birks, & Golder, 2010). This statement calls for a better understanding of the structures and processes where engagement occurs, and how the views of patients, including youth, are valued.

Stomski and Morrison (2017), in a qualitative meta-synthesis of participation in mental healthcare service design, posit that, despite being viewed as an integral component of contemporary mental health policy and clinical guidelines, “participation remains a policy aspiration” (p. 1). Existing reviews at this level of participation document consistent requests for more information, involvement in decision-making. In mental health, Simpson and House (2002) found that involvement of users as employees of mental health services led to clients having greater satisfaction with personal circumstances and less hospitalization; also notable was that providers of services who had been trained by users had more positive attitudes toward users, suggesting possible positive shifts in future professional practice as a result of this form of engagement. and the provision of more substantive care choices (Paul, Street, Wheeler, & Singh, 2015).

Citizen/Public Engagement and Youth Activism

Finally, a fourth area of scholarship that holds relevance to the youth engagement dimension of this project is the history of public engagement in the development of Canadian healthcare. Democracy and inclusion are the values shaping this orientation, and although its language is less used and not often seen in the missions of organizations delivering care, I note that the language of youth activism is very much alive in the public zeitgeist at the time of this project.

In the public participation literature, the public is defined as “all those who have a stake in the health system, including users and potential users of care, public and patient advocates, providers and experts who are also citizens as well as taxpayers” (Abelson & Eyles, 2002, p. 1). This notably broad category — i.e., everyone — does not specify particular categories of the public and does not explicitly attempt to reach voices previously marginalized from participation by virtue of their age or social location. Some scholars argue that public engagement is especially warranted within Canada's publicly funded healthcare system because the public are both the main funders and users of the healthcare system, and as such they are important stakeholders (Born & Laupacis, 2011; Bruni et al., 2008); this

characterization positions the public as a user of services financially invested in their quality, with the values assumption that a customer has the right to demand a certain level of service.

Canadian public participation as it relates to healthcare was articulated for the Romanow Commission (Romanow, 2002) as part of its final report, *Building on Values: The Future of Health Care in Canada*. The rationale for participation was as necessary knowledge input into the design of the healthcare system. Participation is defined as a broad set of practices that includes passive forms of citizen involvement (such as surveys), and more active involvement through direct participation in decision-making processes and structures. This definition has evolved with the development of participation agendas within health research. For example, for the Canadian Institute of Health Research (CIHR), citizen engagement is the meaningful involvement of citizens in policy or program development, from agenda-setting and planning to decision making, implementation, and review (Karazivan et al., 2015).

Public participation also encompasses citizen engagement and deliberative democracy. Salient in the Romanow Commission's discussion paper on citizen participation was awareness of the tensions inherent between views of participation. The first rationale for participation is as an essential element of successful democracy, inherently desirable in its own right; related to health, participation best aligns with Canadian values of universality and equity. A second rationale for participation is instrumental, as a means of achieving something else, such as a particular decision or outcome, a desire for more informed, accountable or legitimate decision making, or a means to delay or share the blame for a difficult decision (Mitton, Smith, Peacock, Evoy, & Abelson, 2009). This rationale for public engagement has broadened somewhat in recent years, with more recent scholars noting that the objective of obtaining information from the public about its needs and preferences is to design a responsive health system (Bruni, Laupacis, & Martin, 2008) and to support quality improvement processes towards improved care (Baker, 2014). Citizen users, state Bruni and colleagues (2008), are often "the most appropriate individuals to provide this information as they can articulate service needs, gaps in service availability, or problems with service delivery" (p. 4).

Constructs supporting public participation and engagement have evolved over the past five decades. For example, Arnstein's ladder of citizen participation (1969) provided a conceptual model for policy makers and practitioners promoting citizen involvement in the health domain, with the metaphor of ascending into higher levels of participation leading to a top level of, for example in the youth participation domain, "youth-initiated, shared decisions with adults" (Hart, 2008). In 2000, Health Canada adapted a Public Involvement Continuum framework to capture the range of purposes and the depth to which the public can be informed, involved and engaged by healthcare organizations.

In 2008, the Canadian Institutes of Health Research (CIHR) developed a Framework for Citizen Engagement. This Framework establishes guidelines for implementing a more systematic approach to consulting and engaging citizens. These include: assessing the merit and relevance of research applications, developing strategic plans, setting research priorities, and strengthening their role on CIHR's governance committees

As abstractions intended for universal and, by extension, tailored application, most models for participation lack conceptualization about context, including either the features of the context that hinder or facilitate involvement and its effectiveness, or, more broadly, the *reasons* a context may want to involve the public (or both). This last aspect is crucial, as the public participation literature shows a great divide as to the values driving social participation.

The presumed trajectories of citizen input into system improvement are unclear, and evaluation of citizen participation is deemed to be lacking (Thurston et al., 2005). Scholars concerned with youth activism draw insights from the interdisciplinary field of political socialization, which is itself informed by communications, political science, developmental psychology and sociology, to explore how youth engage in the political process. Emerging empirical evidence in this area is starting to challenge the "deficit model" (Osler & Starkey, 2003), which has predominantly characterized youth as "incomplete members of society who have to be taught how to correctly engage with politics" (Earl, Maher & Elliot, 2017, p. 3). Increasingly, scholars recognize that youth are not politicized by others, but instead employ the raw materials provided — such as knowledge, models and reflective matter, along

various forms of feedback — to synthesize these materials individually and collaboratively, in ways that make sense to them (Maher, Earl, & Elliot, 2017).

Researchers in this area discuss the barriers to engagement that are created by the assumption of disengagement, or the insistence upon adult-led socialization that denies youth agency upon their process of becoming politically engaged (Elliot, Earl, & Maher, 2017). In a study of the nature of the space set out for youth through youth advisory councils, Taft and Gordon (2013) found that adult-directed political socialization is incongruent with how youth perceive themselves. The nuanced balance between support and intrusion on the part of adults has been highlighted in this literature. For example, Taft (2014) found that intergenerational relationships are always at risk of falling into ageist habits that give primacy to the voices and opinions of adults, at the expense of youth.

Another interesting area of focus in the literature on youth activism has been the understanding of barriers to participation, particularly for minority youth. Various researchers in this area posit that the same processes that prompt activism often pose barriers for participation. For example, Negron-Gonzales (2014) showed that, for undocumented youth, the risk of deportation poses a risk for participation. Kwon (2013) showed that, for youth of color, the assumption that they are at risk of criminality means that acting ‘uncivilly’, such as jay-walking, runs the risk of incarceration. A suggested learning from this area of scholarship is the vicious cycle of exclusion, or non-participation, stemming from negative experiences with societal structures. This is particularly important in efforts that seek to engage youth who have had negative experiences with mental health services, since it is their views that would most directly indicate areas for improvement in how care is designed and delivered.

Mental Health Services Research and Youth Engagement

When applied to youth mental health services research (MHSR) in Canada, engagement is most commonly an amalgam of all the areas discussed above. More specifically, descriptions of YE initiatives display the values of patient involvement and positive youth development, implemented through a participatory orientation. However, these values may be interpreted or implemented differently by the different actors involved in *enacting* engagement, who operate from disciplines ranging from public health administration to social work, child and

youth work, or counselling and psychology. In addition, YE initiatives unfold in practice and knowledge-sharing contexts that have traditionally employed clinical and/or health services research and evaluation approaches. This complex mix occurs in the context of diverse policy pressures to engage (Mental Health Commission of Canada, 2012), and amidst a popular zeitgeist where youth have gained, at minimum, a loud symbolic voice.

I draw attention to the diversity of values, practices and aspirations that combine in youth engagement activities to highlight the fact that implementation is a complex, fraught undertaking. The motivations behind engagement may range from the idealistic to the instrumentalist, communitarian, educative and expressive — or the pragmatic wish to increase accountability. Nonetheless, the realities of funding deadlines and implementation persist and shape, to varying degrees, the way projects ultimately proceed.

Indeed, recent projects in Canadian mental health services research demonstrate the hybrid approach to illustrate some of the benefits and challenges of YE toward the goal of system enhancement. Although many do not explicitly align with a participatory methodology, or employ the existing models of engagement, they often cite collaboration or a youth-centred orientation as their driving principles. In doing so, they highlight both dimensions of collaboration and the function of engagement in exploring community needs. For example, Brownlie, Chaim, Heffernan, Herzog and Henderson (2017) engaged youth as collaborators as well as respondents in a multi-sectoral project designed to enhance youth substance use services, and to support implementation by tailoring findings to local contexts. They applied ‘youth focus’ as an operational principle of their collaborative model, recognizing that “youth knowledge and perspectives are crucial to inform system change that will be responsive to youth needs” (Narendorf, Fedoravicius, McMillen, McNelly, & Robinson, 2012, in Brownlie et al., 2017, p. 137).

Ongoing efforts notwithstanding, youth engagement broadly and in MHSR merits further articulation of its outcomes at the organizational and system level. The challenge of evaluating at this level remains limited by the diversity of contexts undertaking youth engagement values, and the scarcity or low application of theoretical models to inform research and evaluation.

Chapter 3

Chapter 3: Developing the Study

This study used Institutional Ethnography (IE) as a complement to methodologies used to investigate YE to date. An approach developed in the field of sociology, IE focuses on the perspectives of people in their daily lives to trace how their experiences constitute and are constituted by the external, structural and social relations in which they are situated (Smith, 2005). IE is suited to generate a descriptive understanding of how certain forms of knowing can replace, undermine and/or also uphold other forms of knowing (Smith, 1987). This process is accomplished through its grounding in the words and experiences of informants as they enter into relationships with organizational and institutional processes.

In this chapter, I present the research questions for this project, provide the rationale for my use of IE, and describe relevant IE constructs employed in the conduct of the study. A key reason for my choice of IE lies in my own history as a coordinator of youth engagement in various mental health and research initiatives. I discuss this positionality as a factor in developing this particular line of inquiry in the second section of this chapter. In the last section, I detail the study processes, describing groundwork, sampling, data-gathering and analysis procedures, as well as considerations of ethics and rigour taken through the conduct of the research.

Research Questions

The overall purpose of this research was to provide an in-depth examination of processes in youth engagement, thus deepening critical understanding of how mental healthcare actors and services approach youth. The principal questions asked were:

- 1) What does transformative youth stakeholder engagement look like?
- 2) How is the work of transformative youth engagement envisioned by an organization? How does it occur?
- 3) In what ways does transformative youth engagement impact the development and delivery of appropriate care?

Secondary questions were:

4) What are barriers and best practices in incorporating youth-generated knowledge into mental-health service practice?

5) How do trans-local, embedded and nuanced relations shape the role of youth as knowers in the mental healthcare system?

Institutional Ethnography

Institutional ethnography (IE) was considered to be an appropriate methodology because it provides the means to focus on people's experience of youth engagement, specifically on how youths' knowledge may be enacted, and also shaped by, the coordinating influence of forces external to the local setting. IE is a materialist method of inquiry developed in the 1970s by Canadian sociologist Dorothy E. Smith. It focuses "on how things happen" (Campbell, 2003, p. 3). IE is materialist in its central concern with the actual, daily, social relations between individuals, what Marx and Engels described as "real individuals, their activity and the material conditions of their life" and which Smith suggests also grounds a feminist sociology (Marx & Engels, in Smith, 1987, p. 144). Central to IE's feminist roots is its commitment to interrogating "taken for granted practices of knowing" (Campbell & Gregor, 2002, p. 7) by grounding an inquiry on what is seen and heard of people's activities, and then tracing up into the discourses and textual materials that shape these activities. In doing so, IE makes visible how people's everyday experiences are coordinated by forces outside of their local and everyday knowledge, what Smith describes as "put together by relations that extend vastly beyond the everyday" (2005, p. 1).

IE inquiries that were formative to the conceptualization of this study focus on the question of whose knowledge counts when it comes to the design and operation of systems of care. They investigate the different degrees of agency held by actors within an institution, and the ways information infrastructures that are meant to facilitate their work can both promote and exclude certain forms of knowing. An investigation by de Montigny (2014) on the experiences of child protection work crystallized for me the power of IE to link the local and experienced to the trans-local and structural. de Montigny relates his experiences as a social worker in the process of apprehending a child for protective custody. In near-

phenomenological detail, he describes the embodied experience of seeing, smelling and touching what this child and his mother experience every day. He shows that his work engages him physically, cognitively and emotionally with the long-standing challenges and disadvantages that this young, racialized and impoverished mother experiences. de Montigny then contrasts his experience at this child's home to the textual infrastructure that supports — but also coordinates, rules and restricts — his work, describing the language necessary to fill the forms and bulleted lists of options that build an institutionally acceptable case for protective custody. de Montigny's description of these two contrasting dimensions of his work reveals all the intricacies of the child's, and his mother's, situation as subjects of a protective custody process. It underscores how the massive complexity of a person's intersecting disadvantages are not given justice, but are instead channeled into and flattened by the demands of textual, institutionalized reporting. Under such demands, emerging and long-held expertise on the part of the child-custody worker is circumscribed to a limited number of characters on a page. de Montigny (2014) describes how the mother's story is effectively silenced: "The report to the court did not address her situation nor her understanding of what it meant to be a First Nations person, a young woman (nineteen years old), a single mother, a woman who had dropped out of school in grade 8, and who had struggled with a physical disability throughout her life," (p. 180). IE served to link these lived experiences to the textual infrastructures that the service provider must engage with, and thus revealed how the work of child protection is both constituted by and constituting a faulty machinery of discursive elements that have real-life consequences.

Many IE scholars have displayed an interest in describing how changes happen in the front-line work of organizations delivering services to people (Griffith & Smith, 2014; Rankin & Campbell, 2009). Though not directly applied to mental health services research or patient engagement, some of these investigations have been relevant to my approach in this study. For example, in his investigation of evidence-based medicine (EBM) as a text-based mediation of governance, Mykhalovskiy (2003) described the problematization and evaluation of physicians as "indifferent readers" (p. 338), holding their reading behaviour as the object of critique, under the new demands of EBM. Webster (2009) extended Mykhalovskiy's argument in an IE of the social organization of best practice for acute stroke, showing how different groups of physicians (academic specialists) come to hold an

evaluative gaze over physicians in the community. This problematization of community physicians, Webster notes, produces “a discourse that constitutes them as the barrier to the provision of best practice care” (p. 31), while directing attention away from how best practices are developed and constructed. Both studies demonstrated how IE allows for the expansion of a conventional social critique, and provides the tools to undertake a more nuanced investigation of the relationship between the promising and limiting aspects of a particular discourse.

A new vantage point for studying youth engagement.

Similarly, the role of adults — be they researchers or service providers — has been the object of critique and rehabilitation by much of the discourse relating to youth engagement. The adults in the youth-adult dynamic are often constituted as creators of tokenism, indifferent partners, or barriers to genuine change. In this study, I aim to move away from binary assumptions about the role of youth versus adults, and instead shed light on the contextual and structural dimensions that support or constrain whether or how youths’ knowledge enters the design and delivery of mental healthcare.

No published studies were found that used Institutional ethnography to investigate youth engagement. IE operates with different objectives and approaches from those of Positive Youth Development and Participatory Research, the scholarly area and research approach where most of current knowledge of YE resides. Instead, IE holds in its feminist roots a commitment to the democratization of knowledge practices and the socio-critical project of justice that aligns with — and expands — the ways youth engagement has been studied to date. In employing IE, this project was designed to further what we know of YE by looking at it from a different vantage point.

This vantage point is accomplished in IE through the process of ‘tracing up’. IE conceptualizes participants as expert informants, relying on their accounts as the starting point for inquiry, then driving analysis upwards towards a macro understanding of trans-local activities, discourses and values — termed within IE as ‘ruling relations’ (Smith, 2002, 2005). The research process does not rely on any overarching theory or framework; instead, IE promotes the use of distinct and nuanced conceptualizations of everyday terms to connect the micro and macro, in order “to illuminate the forces that shape experience” (Smith, 2002,

p. 32). The empirical process relies on use of these specific terms, noting their emergence through data-gathering and analysis, and positioning them within constructs to guide the inquiry. Concepts such as ‘work’, ‘informant’ and ‘institution’ hold specific meaning within IE, expanding and clarifying boundaries of the conventional usage of the terms, in order to illuminate more about the institutional focus of the inquiry. Similarly, constructs such as ‘the problematic,’ ‘standpoint,’ and ‘institutional capture’ serve to establish the relationship of these terms to one another, and reveal processes and phenomena while anchoring the inquiry empirically. I will now elaborate on each of these concepts and constructs, explaining their relevance to the present study.

Work.

As noted, IE emphasizes ‘people’s doings’ at the level of their everyday experience, in order to illuminate previously unseen dimensions of what they do, and how such doings are coordinated with those of others (Smith, 2005). The materialist concerns of this approach come to life in the way that data collection and findings must consistently focus on the materiality of people’s doings in locations that have substance and matter (Rankin, 2017). The language of ‘people’s doings’ is thus, both a compass through the interview and observation processes, and an anchor in the analysis, thus providing an opportunity for rigour. The concept of work refers to what people actually do in particular places, under definite conditions, and with definite resources (Smith, 2003). This generous definition of work eliminates the distinction between paid and unpaid work and encompasses “anything people do that takes time, depends on definite conditions, is done in particular actual places, and is intentional” (Smith, 2005, p. 210). Diamond’s (1992) ethnography of seniors’ residences describes the time and attention needed to allow an elderly patient to express a fear, share a thought, or tell a story — a waiting that is excluded from the formulary of productive activities sanctioned by the organization. This hallmark IE study draws attention to the narrow range of activities that are recognized and valued by the professionalized industrial model of health care for seniors, in contrast to the actual needs of institutionalized patients. Work is defined as what is reimbursable, trackable and subject to regulation. As Diamond asserts, waiting is also work, but is not recognized as such.

Additionally, I used specific terms as analytic anchors in the conversation, a measure exemplified by Mykhalovskiy and McCoy (2002) in their institutional ethnography of the politics of knowledge-making at the interface of universities and community-based health organizations. They used the term “health work” as an orienting concept and ‘empirically empty’ term, to direct our attention toward the wide range of practices that people engage in around their health, without defining in advance what that work might or should involve,” (p. 24). Similarly, I used the notion of “engagement work” to contain the variety of people’s experiences in the range of youth-adult interactions and in the activities that youth undertook as part of the YAC. For the scope of the study presented here, anything that professionals and youth did that required time and effort, and was intended towards the concerns of youth mental healthcare was highlighted as a form of engagement work.

As was identified previously in the scholarly literature on youth engagement, most research-based descriptions of YE are abstract accounts that do not connect the actual work that adult service providers do with the existing contextual opportunities and barriers for effective engagement. In this project, the IE conceptualization of work was used to identify various dimensions of youth engagement, through the experiences of youth and adults, as a means to keep the institution of “youth mental healthcare” (see below) in view. Meeting observations and interviews were conducted to reveal the various ways that youth advisors and service providers interact with the organization with intent, effort, and varying degrees of competence. The ways in which such work resulted in the uptake of youths’ knowledge within the organization were explored. I drew upon these concepts of work when talking to informants in order to allow for the possibility of informal or hidden aspects of what is considered “youth engagement” to emerge. Particular attention was paid to dimensions rarely accounted for in professional practice, organizational expectations, or existing discourses or mandates for YE. This expanded concept of work opened more possibilities to see how people’s experiences, including their words and actions, were oriented to the work of others active in the same process.

Ruling relations and institutions.

An important contribution of IE is its potential to reveal how institutional influences are embedded and pervasive coordinators of people’s everyday doings. As noted above, through

the process of ‘tracing up’ from the actualities of informants’ experiences, IE reveals how the everyday, embodied and local can be permeated with and coordinated by relations and institutions that function outside of the local environment. Smith (1987) refers to these trans-local social relations that carry and accomplish organization and control as ‘relations of ruling’ or ‘ruling relations’. Ruling relations both constitute and are constituted by the experiences of people in a particular environment. A useful example of the tension between the local and the trans-local is to think about the everyday experience, as felt in the lives of local people, when a hospital closes. DeVault and McCoy explain (2012), “if the local hospital closes, the explanation will not be wholly local” (p. 382). That hospital’s existence, including its closing, is organized in powerful ways by trans-local social relations that include local, provincial and federal bureaucracy, administration, management, professional organization, and the media. The purpose of an IE inquiry, however, is to deeply, and from perspectives of the people involved, explore their experiences for their connection to trans-local relations of ruling. This purpose is accomplished by looking for traces of ruling relations that arise in the descriptions of work — these are often moments when the work being done by standpoint informants does not seem to be supporting the interests of the people there (Rankin, 2003).

Building on this notion of ruling relations, IE employs a distinct conceptualization of the term ‘institution’ (Smith, 1999). In this usage – for example in the phrase “the institution of psychiatry” or “the institution of healthcare” — the term institution does not refer to a stable organization or a single services site. Instead, as DeVault and McCoy (2006) describe, ‘an institution’ refers to the organizations, agencies, and people that are connected via trans-local relations in order to do work related to a distinctive function, such as healthcare. In IE, the term ‘institution’ directs the researcher’s attention to “coordinated and intersecting work processes that take place in multiple sites ... [bringing] into view a vast nexus of coordinated work processes and courses of action” (DeVault & McCoy, 2002, p. 753) in diverse, trans-local contexts. Smith (2002) lists among this nexus various forms of bureaucracy, administration, management, professional organization, protection services, insurance companies, government ministries and departments, mass media, and medical and nursing schools that could be attributable to the nexus called “healthcare”.

For the purposes of this research, the institution under view was “youth mental healthcare”. But the objective of IE generally, and in this research, was not to map out the entire nature of such institutions. Rather, it was to make visible the connection between the daily experience of service providers in their work to engage youth, with particular aspects of the large complex of actors and activities that form a mental healthcare system.

Standpoint.

The use of standpoint in IE secures an empirical location by focusing on the experiences and activities of a particular group of people. DeVault and McCoy suggests that adopting a standpoint constitutes “a means to anchor the research in the relevancies of a particular group, not suggesting that all persons in that group share a determinate standpoint, or that the perspectives of those outside the group should be ignored or discounted,” (2006, p. 32). In employing a standpoint, “not as a given and finalized form of knowledge, but as a ground in experience from which discoveries are to be made” (Smith, 2005, p. 8), IE provides an opportunity to reframe the nature of YE in the institutional context. Rankin (2017; 2017b) describes that this group of people are positioned within a complex regime of institutions and governance; therefore, learning how the standpoint informants’ experiences are being coordinated is the purpose of the analysis.

In this study, the standpoint used was that of those working in engagement. The problematic of the inquiry was on the work of engagement as experienced by adult professionals. However, the experiences of youth in this process also constituted important data because they, too, were active in such work. In particular, in the positioning of both youth and adults as informants, IE supported looking beyond any individual evaluation of their roles as youth advisors or service providers. It also precluded simplistic potential binaries between youth and adult positions, and avoided essentialist conceptions of youth versus adult concerns. Instead, in maintaining an analytic connection to distal structures, IE enables asking more concretely how it happens that the work of YE (and specifically the uptake of youth’s knowledge) is constricted or underscored in their everyday interactions with the institution.

A commitment to the standpoint of youth advisors and service providers framed them as expert informants in youth engagement — what YE looks and feels like — and how it impacts and is impacted by the organization. Standpoint in IE allows for perspectives from

different locations: in this case, youth and adult informants were understood to be located somewhat differently, subject to different discursive and institutional processes that shaped their activities. However, the point was not to capture their different perspectives, but instead to reveal the invisible institutional coordination of their work, and to illuminate the relevant social relations that could be heard through their accounts, and observed in their meetings. Per IE principles, these two sets of informants were sought to provide knowledge that, rather than revealing more about youth and adults, would inform how the institutional and trans-local shapes their interaction with each other. As noted by DeVault and McCoy (2002), the purpose of an IE investigation is not to generalize about the group of people interviewed, but to “find and describe the social processes that have generalizing effects” (p. 753).

The problematic.

I originally set out to investigate empirically how it was that youths’ knowledge was taken up or dismissed by the adults interacting with them. This line of inquiry was in response to findings in the various literatures on patient engagement, youth engagement, and citizen participation, where the effectiveness of engagement is often problematized as a function of the power differential between youth and adults, while genuine engagement is idealized as a means to effect beneficial change upon the design of services (Bartram et al., 2012). In setting up this study I was intrigued by what I felt was a disjuncture between the discourse of engagement developed in YE mandates, and the actualities of engagement in practice, as experienced by the adults supporting that engagement within the organization.

Seen through an IE lens, this disjuncture (Rankin, 2004; Smith, 1987, 1999, 2005) at the core of engagement is what Smith calls a “problematic of the everyday world” (Smith, 1987, p. 91). Stooke (2010) has described this idea as a “vague but nagging and persistent concern about a situation whose determinants seem to elude those people most affected by it” (p. 289). The ‘nagging and persistent concern’ in this research was that the adults that interact with youth become an object of critique while, in my experience, much of their work is values-aligned to support youth and the inclusion of their perspectives. The pressure to engage exists, even when there are not sufficient training resources, institutional supports, or coherent evaluative tools to create and assess genuine engagement. This problematic served to organize the research direction of the project from the ‘standpoint’ of the professionals,

focusing on the work that they do to engage. In relaying the study findings, I will elaborate on this problematic, describing its appearance in the experience of youth engagement on the part of the adults tasked with YE.

Institutional capture.

The construct of institutional capture reveals the complex relationship between informants, the researcher and the institution, while also giving a lens to observe the fact that ruling relations coordinate people (and are coordinated by them) in a process that is constantly in flux. Institutional capture (DeVault & McCoy, 2006; Smith 2003b), as employed in IE, refers to a susceptibility on the part of the informants and the researcher to be “captured” by the discourse and other forms of ruling of the institution, and thus organized by them even as the inquiry unfolds. Smith (2005) describes that “the interview situation is subject to ‘institutional capture’ particularly where both the informant and the researcher are familiar with institutional discourse and know how to speak it,” (p. 156). A maxim of IE is that research should begin outside the institutional discourses (McCoy, in Smith, Ed., 2005, p. 122). Some institutional ethnographers warn of the dangers of institutional capture, suggesting it leads to empty data. McCoy says: “Despite your intentions, if you are conceptually beholden to the institutional discourse, if you treat the institutional language as merely descriptive and attempt to use it that way in analytic writing, the opportunity to investigate the institution has been abrogated,” (in Smith, Ed., 2005, p. 122). This warning rings true, and aligns with other researchers’ recommendation to be alert for the emergence of institutional discourse through every phase of an IE investigation. Reflecting on IE investigations in community- and human-service sectors, Nichols (2016) notes that “participation in institutional discourse is a key feature of professionalism across the human services” (p. 18). Institutional discourse, then, stands in contrast with the language of persons outside of the professional processes of the organization, including youth; it provides a point of entry into the problematic of diverse knowledges and potential devaluing of previously excluded forms of knowing.

The construct of institutional capture has also been harnessed by some IE researchers to reveal how people work with the institution, negotiating barriers and facilitators in its structure, with resulting impacts. Smith (2005) says that, “rather than view institutional

discourses as prescribing actions, we might see them as providing terms under which what people do become institutionally accountable or recognizable,” (p.113). Eastwood (2006), in an investigation of UN forest policy negotiations, identifies that one way of influencing the process at hand is through engaging in a form of intentional institutional capture. In doing so, people are constrained to translate their experiences and “interests” into something that is recognizable, manageable and palatable to the organization.

In the process of this research, the construct of institutional capture became a self-reflexive tool that provoked vigilance against letting the institutional discourse subsume or displace descriptions based on experience. As well, in this project, the construct of institutional capture offered an important lens through which to question and examine the nature of youth engagement, and in particular its capacity to create change in, or transform, the organization.

As Rankin (2017) notes, “in IE, important analytical thinking begins prior to the start of formal fieldwork and data collection.” The technical terms of the problematic, standpoint, and institutional capture provided empirical and conceptual scaffolding through my progress in this research, starting from the initial motivation for inquiry, in shaping the nature of interviews and analysis, and in the conceptualization of engagement which anchored the study. These concepts don’t operate in linear or independent ways, but instead inform and develop one another in iterative ways. In the interest of clarity, three distinct vignettes that describe the use and relevance of these three IE concepts will be used to synthesize and complement study findings for each of the primary research questions.

Autobiographical Research Narrative

A significant consideration towards maintaining rigour in this investigation has been continued reflexivity as to the research process and my own role within the system and institutions I am attempting to describe. What follows constitutes what some Institutional Ethnographers call an “autobiographical research narrative” (Mykhalovskiy, 1999) that, rather than treating researcher’s presence as a bias that must be overcome (Campbell & Gregor, 2002), seeks to illuminate the ways my own position alters and shapes the account I share.

The YAC in this project is not the first youth advisory council with whom I talked. For six years before this research study began, I worked as a YAC coordinator in a national participatory research project, and as a coordinator and advocate for youth engagement in mental health service design representing a national not-for-profit organization. In that role, I delivered training to adults and young people on the how-to's of engagement in various research and service-delivery projects in the mental health sector. In 2015, I delivered a workshop to the entire ACCESS OM Network during its first meeting as a national entity, and a few months later led a two-day training for its principal investigators and YAC.

My motivation to undertake this research stems from these work experiences. In the role of an adult striving to bring youth perspectives into research and healthcare institutions, I have experienced the barriers for uptake from the standpoint of a professional who did not have sufficient power within the system or organization to actually effect change. I have coordinated engagement in roles in large universities where it became clear that, as much as youth needed to be paid a living wage for their contributions — and to be paid in a timely manner so that they could make their rent payments — the pace of processing invoices and finances within a large university was not going to meet their needs or make them feel valued. I also know that youths' shared experience that the amount and timelines of such payments was not working for them did little to change the bureaucratic processes and budget priorities of the university engaging them, despite the attempts to make such a change on the part of the adults in the research team.

This position has predisposed me to vigilance of the relationship between individuals and institutions — and the value accorded to the individual, and specifically to youth, by large bureaucracies and organizations. This vigilance is how I navigate the tension between the values I know I hold, and my own capacity to apply these values in my working life, to effect change.

My visible position as an advocate for youth engagement altered how the YAC, the service site, and even members of the National research team supported this study. It made my entry into this world easier, and my approach to the issues more complex. Consistent with the aforementioned concept of “institutional capture” (DeVault & McCoy, 2006; Smith 2003), I found myself in situations in which the informants and I shared the same institutional

language: while transcribing interviews, I realized just how much laughter there was in our conversations, how many moments of presumed shared values. My previous roles made it easy for informants to open up and trust me because I visibly held aligned values; it also provided opportunities where we could have easily glossed over the very terms that need deconstruction.

In describing her disparate roles as mother and academic, Smith has introduced the notion of ‘bifurcated consciousness’ (Smith, 1987). In a similar manner, through the conduct of this study, I began to notice my role with regards to engagement holding this tension and duality. Regardless of my employment circumstances, YE is linked to my personal commitments to human rights, health equity and justice, and the belief that it is ethical and just to include the perspectives of users of a health system into its design and operations. I feel lucid confidence in these principles. Yet, I also feel we must remain critical and prepare to question the unintended consequences and any normative ways of operationalizing YE principles. As other researchers in Y-PAR have stated, it is important to go beyond good intentions (Berman & Jiwani, 2014; others)

As a researcher, it is clear to me that this work, its findings and recommendations, will only be effective to the degree to which this knowledge informs policy and practice. The quality of my engagement with the people in this mental health services organization does not stand alone, but thus enters into relationship with my own work processes and timelines, and with others’ timelines and priorities. The values, demands and realities of the institution of academic research, and of publishing and other mechanisms of dissemination, will also play a determining role. In other words, the legitimacy of those moments of engagement is, in part, outside my control. Whether I engaged genuinely enough may be shaped by institutional and organizational spheres much more than it is by our laughter and connection in the moment. Nonetheless, I am responsible, and it is my job to ensure that what the informants shared is taken up, in some way.

This study begins at the place where what youth know enters the context of the organization. It looks for the ways that service providers in the organization not only hear but also *share and implement* what youth have said into the design of services. In examining this, I did not treat the service providers’ responses to youth as a set of individual problems to be resolved.

Instead, I took up the service provider's standpoint to begin to explore and understand the forms of work and the coordination informing this type of engagement with youth. My study does not enter into the evidence debate as to whether or not the evidence from youths' lived experience is sound. I do not attempt to make claims about individual service providers' beliefs, attitudes, or psychological characteristics. Instead I sought to ask what this type of engagement looks like in this particular context, in an attempt to render visible the forms of coordination — the ruling relations — that organize it.

Research Methods

One of the characteristics of Institutional Ethnography as a method of inquiry is its lack of a pre-determined sequence of research activities (Campbell & Gregor, 2002). DeVault and McCoy (2002) describe the process as “one rarely planned out fully in advance ... [where] the researcher knows what she wants to explain, but only step by step does she know who she needs to interview, or what texts and discourses she needs to examine” (p. 75). This study unfolded in a similar manner, with the persons to be interviewed and the texts to be examined unfolding as the research progressed. Table 1, below, details the timeline of the research process.

Table 1: Timeline of Research Progress

RESEARCH PROGRESS TIMELINE

October 2015	▪	Groundwork with the ACCESS OM Project
November 2016	▪	Groundwork with the local service site
October 2016	▪	Ethics application and approval Western University REB
March 2017	▪	Ethics application and approval local service site
April 2017	▪	Data gathering phase 1: Interviews and observation (6 months)
September 2017	▪	Transcription, analysis and group presentation/discussion
December 2017	▪	Integrated knowledge translation and discussion with service providers
February 2018	▪	Transcription and analysis: Questions 1 to 3
September 2018	▪	Analysis of textual sources; Questions 4 and 5
December 2018	▪	Writing up of study results

This study entailed approximately one year of groundwork with the service organization and ACCESS Open Minds (AOM) Network leading up to the local ethics review board application and data gathering process. In part due to my prior roles in engagement described above, I was present at AOM-Network-wide meetings and the local opening of the ACCESS OM initiative at the research site. I also held individual meetings and phone calls with administrators in the organization, with the purpose of discussing the aims of this project and to define shared knowledge generation and translation goals. This collaborative tenor to the project continued through the fieldwork and analysis process, and led to the joint creation of knowledge translation vehicles and joint presentations at research conferences.

The data.

IE makes use of several types of data, including interviews, observations, and texts, with some researchers in IE making a distinction between first-level and second-level data (Campbell & Gregor, 2002). First-level data involves careful descriptions and observations of everyday life; in this research, this type of data included meeting observations and informant interviews.

Individual interviews.

Fieldwork for this study took place over the course of six months. It was comprised of iterative observations (below) of the working group and advisory council meetings at the site, and individual interviews with adult professionals and youth participating in these working groups, and in the YAC overall.

Initial interviews were approximately one hour in length, and were based on two semi-structured interview guides developed for youth and adult professionals as a loose framework for conversation (see Appendix I and Appendix II). Initial interviews were conducted with 10 informants; 4 youth and 6 adults. Interviews were recorded, with participant permission, and transcribed verbatim. Follow-up interviews and conversations with the informants, individually and in groups, were conducted to deepen particular lines of thinking that arose during fieldwork and analysis. These meetings had the dual purposes of analysis and joint meaning-making towards the creation of a conference presentation and a research poster. These follow ups were conducted with the YAC and Family Advisory Council (FAC), and with four adult service providers.

Interviews in this study focused on the lived experience and everyday language of persons interviewed, with participants encouraged to use their own, everyday words, to relay their own experience of work, defined broadly or “generously” (Smith, 1987). Interviews proceeded somewhat differently from conventional forms of interview research, in that informants’ accounts were not intended “as windows on the informants’ inner experience” (DeVault & McCoy, 2001), but were designed to reveal the organizational and institutional processes that shape local experiences. The goal was to build an empirically informed argument based on material practices occurring in the setting explored. The fairly loose structuring of interviews supported analytic thinking at the interview stage because it allowed privileged participants’ telling their own stories in their own words, in their own ways. Following this principle, the analysis emphasized the social and organizational arrangements as they emerged in the everyday experiences, and everyday speech, of the informants. At times, interviews departed from the interview guide in order to look for something outside the experiences of key informants that may have been largely invisible to them, but somehow entered and coordinated their work with those of others. Similarly, talk in these interviews

aimed to deepen the insights and pursue particular lines of thinking that arose during fieldwork and observation. The overall aim was to expand understanding of the relationship between people's everyday work together and the trans-local relations that organize and coordinate youth-adult engagement.

Second-level data involves finding the organizational details that are missing from these experiential accounts, a process that is accomplished through shorter exchanges and emails, or through textual sources. Because a central component of IE is the conceptualization of social life as discursively organized (Campbell & Gregor, 2002), second-level data in this study has included texts, including the scholarly and grey literature on youth engagement. Integrating institutional texts into ethnographic practice extends its scope beyond the observable (Smith, 2001). Analyzing the practice discourse of YE, by examining the manuals, toolkits and training resources that guided the practice of YE, allowed me to link youth and adults' accounts back to that discourse, to see how it becomes enacted in the social settings of their everyday lives.

Observation.

Observation of the meetings involving youth and adults constituted the main context for investigating the interaction between YAC youth stakeholders and adult service providers in the organization. Observation took place onsite, and focused on three types of meetings: Operations Working Group, Facilities Working Group, and Youth Advisory Council. Observation in IE is meant to elicit detailed descriptions of work in order to "make visible the institutional hooks and traces, as well as the lived experience of the teller," (McCoy, 2006, p.111). The aim of meeting observation in this project was to *see* engagement at work, and in particular to identify moments when the knowledge brought by youth stakeholders interfaced with the organization and its operations. A particular focus of this process was to note how youth and adults communicated with each other, and what service providers did with the information that youth shared with them. Research memos resulting from meeting observations captured the types of language and forms of knowledge that youth and adult participants mobilize during their interactions. I took note of tensions and opportunities that arose when different forms of knowledge emerged. I took note of who spoke, when and how; but also, who responded to and took up the statements uttered, and employed them to further

the discussion. I was also interested in the overall development and sequencing of meetings, with particular attention to how agendas were set and followed, the leadership style and organization of actions forward, and the disciplinary tone of proceedings. Observation of meetings served as a starting point for deeper inquiry through individual interviews.

Informants.

Informants were selected to represent both the Youth Advisory Council population and the adult-professional group that interacted with them through YAC and ACCESS Open Minds activities. In keeping with IE, there was no proscribed number of informants; rather, the emphasis was placed on features of experience, diversity, and social location of the persons interviewed (Bisaillon & Rankin, 2012, p. 4). Within the group of youth advisors and service providers employed at the research site, I sought out informants for their first-hand experience with the issues or processes of YE. Selection was purposeful to represent a range of experiences within the project model of youth-adult collaboration. There was a single criterion for youth inclusion as informants in interviews: that he/she/they be a member of the Youth Advisory Council. Four YAC members were interviewed over the period of six months; their ages ranged from 17 to 29. As well, seven adult professionals — whose roles range from leadership to peer-support positions — were also interviewed during that time. Criteria for adult participants were: 1) That the adult be an employee of the service organization; and 2) That this person's role include interaction with youth from the Youth Advisory Council (YAC) and/or with activities pertaining to ACCESS Open Minds project at the local service site. All of the adult professionals had had opportunities to work with youth in the organization and/or via the YAC. As noted by DeVault and McCoy (2001), the purpose of an IE investigation is not to generalize about the group of people interviewed, but to “find and describe the social processes that have generalizing effects” (p. 753).

Texts.

I identified texts for analysis throughout my fieldwork. The question I continuously asked myself was: “What organized this work?” This question was sometimes answered directly by the informants: they either referenced or shared texts they felt had guided them or framed the expectations of their work. At other times, what organized the work of YE was less explicit to the informants themselves, and became visible as I re-read the interview transcripts, noting

particular language that signaled the entrance of the YE discourse — namely stock phrases or institutional ways of ‘explaining’ their experiences. This entrance of the trans-local is what Diamond (2006) calls “a particular moment hooked into the ruling relations” (p. 46).

Interviews with the informants contained many instances of such activation of the YE discourse. Terms relating ‘youth friendly’, ‘youth leadership’, ‘youth power’ and ‘empowerment’ were common in the descriptions offered by YAC members, particularly those of long standing in the Council, and some adult informants. Through the course of the initial interviews and all subsequent communications, I continued to ask the adult informants about texts that could be included for analysis. As listed in Table 2, below, I identified a total of eight texts from provincial, federal and international levels. For ease of reading, I have assigned an acronym to each text, and have followed the acronym with a designation of -P, -N, -I to denote its provenance. These eight texts were created by four non-governmental agencies (EEYO-N, EYCD-I, YET-P, and YI-P); three government-endorsed committees (MHCCPSG-N, SPOR-N, and MHCCTAY-N); and the community-responsibility program of a private pharmaceutical company (EYCHS-I).

Table 2. Youth Engagement Practice Texts under Analysis

Practice Area	Jurisdiction	Title	Text Descriptions/Creators	Intended Audience or Tool Description	Year	# of Pages
Community Development	National Non-governmental	Exploring Engagement with Youth Organizations: An Initial Step EEYO-N	Centre of Excellence for Youth Engagement led by The Students Commission	Survey of 78 youth-serving organizations across Canada to find out how youth engagement happens in their communities.	2002	1
Community Development	International Non-governmental	Engaging Youth in Community Decision-making EYCD-I	Center for the Study of Social Policy, Washington, DC	www.int-initiative.org An international network of policy makers, managers, practitioners and	2007	94

				researchers—as well as youth and adults from 4 countries—focused on youth involvement in community change.		
Mental Health System Design/Research	Provincial Non-government	Youth Engagement Toolkit: Ready... Set... Engage! Building Effective Youth/Adult Partnerships For A Stronger Child And Youth Mental Health Systems. YET-P	Pereira, N. Ontario Centre of Excellence for Child and Youth Mental Health	Community and health service organizations in Ontario and Canada.	2007	76
Mental Health System Design/Research	National Non-governmental organization	Youth Involvement YI-P	mindyourmind	Service providers, researchers and organizations serving young people.	2014	2
Mental Health System Design/Research	International Government-endorsed committee	How to Engage Young People HTPYP-I	Orygen Australia	Mental health service organizations in Australia and internationally.	2016	3
Health Services Design/Research	International Pharmaceutical Company	Engaging youth in the creation of their own health states: Youth Engagement Toolkit EYCHS-I	Astra-Zeneca Young Health Programme in partnership with Plan International, Johns Hopkins Bloomberg School of Public Health and mindyourmind	This toolkit is intended for health practitioners, policy makers, and people that serve young people.	2013	8
Health Services Design/Research	National Government-endorsed committee	Strategy for Patient-Oriented Research: Putting Patients First SPOR-N	Canadian Institutes of Health Research	SUPPORT Units and Networks stakeholders (patients, researchers, health care providers and decision-makers)	2014	11
Mental Health System Design/Research	National	Mental Health Commission of	Emerging Adult Innovators Panel and Jury, Mental	Provincial and territorial policy	2017	41

	Government-endorsed committee	Canada. (2017). Consensus Statement on the Mental Health of Emerging Adults: Making Transitions a Priority in Canada MHCCTAY-N	Health Commission of Canada	and program decision-makers		
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Analysis

Analysis of interviews and meeting observations.

Analysis of interviews and meeting observation was guided by the IE commitment to remain grounded in the experiences of youth and adults, as well as the words they chose to describe their experiences (Devault & McCoy, 2006). In IE, analysis is an iterative and inductive process that, as Bisailon and Rankin (2012) describe, “begins in the first interview and continues through write-up of the results,” (p.4). Analysis was started at the stage of initial interviews and meeting observations. I recorded and transcribed the interviews, and recorded the meeting observations through field notes and research memos. I then reread the transcripts and research memos to distill salient groupings related to the research questions, seeking out clues to the connection between the individual experience and trans-local, coordinating organizations, discourses and norms. The intent was to uncover the social organization of the everyday experience within the service site. To accomplish this type of indexing, I drew on the work of Bisailon and Rankin (2012) for additional support in the analytic approach. In their Table 1: Characteristics of interviews using institutional ethnography (Appendix I), Bisailon and Rankin compare the analytic concept, referring to a way of inquiring through the interview, with the analytic intent of such a form of inquiry.

Analysis of texts.

I used Framework Analysis (Ritchie & Spencer, 1994) to analyze the texts referenced by the standpoint informants as part of the practice discourse of YE. Framework Analysis is suited for applied policy research, and is considered to be better adapted to research that has specific questions, a limited time frame, a pre-designed sample and *a priori* issues (Srivastava & Thomson, 2009). Although Framework Analysis may generate theories, the

prime concern is to describe and interpret what is happening in a particular setting in a stepwise manner (Ritchie & Spencer, 1994). In this case, I describe ‘the setting’ as the practice discourse of YE. In keeping with the Framework Analysis approach, I undertook the following stages: 1. familiarization; 2. identifying a thematic framework; 3. indexing; 4. charting; and, 5. mapping and interpretation. My process for conducting this analysis was to read these texts repeatedly, making notes of the similarities and differences between them. The thematic framework used, as well as the charting and mapping/interpretation applied, were based on questions generated through the course of this investigation, beginning with the analysis of the scholarly literature on engagement, and grounded on the problematic of the study. This approach is consistent with the aims of IE, namely to pay attention to *how* the issue is known, and in particular to how, as Rankin (2017) aptly describes “it rests on a scaffold of concepts and theories that have been abstracted from any concrete descriptions of people doing things” (p. 5). The questions I employed to conduct this analysis are:

1. How is YE defined or conceptualized?
2. How is the problem YE addresses defined? How was it made to be a problem?
3. What are the underlying values and principles of YE?
4. How are youth and adults conceptualized?
5. How is YE described in relationship to the context and knowledge processes in the context?
6. What is invisible in these resources and policies?
7. What approach to youth engagement does this discourse contribute to?

Tracing up to answer the study questions.

Using the data gathering and analysis methods described above, I gradually traced up through the research questions, identifying additional sources of data. Figure 1 below illustrates the tracing-up process to answer questions 1 to 3.

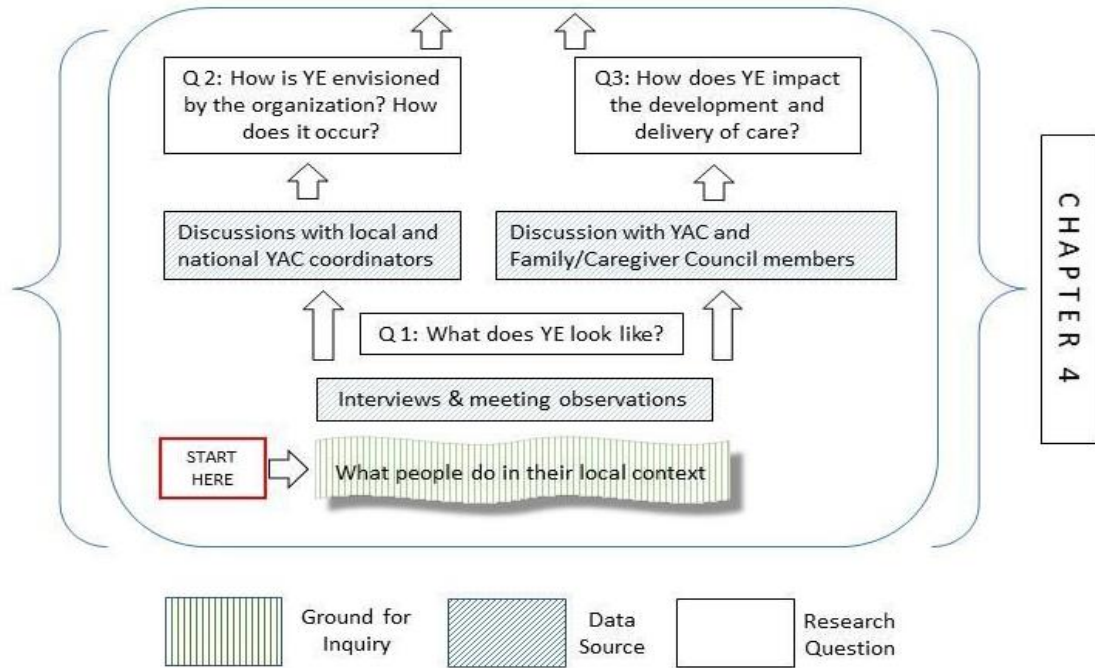


Figure 1: Data-gathering process for questions 1 to 3.

The process of answering Question 1 describes the work of youth engagement based on the initial interviews and observations, and delving into the informants’ experience with the organization. The data focus on youth and adults’ descriptions of YAC meetings and their history as YAC members or service providers supporting engagement, combined with observation of meetings with organizational and community stakeholders and among the youth advisors themselves. The analysis here was focused on revealing how the work of engagement happens, as described by both sets of informants.

Analysis of data in relation to Question 2 — how transformative youth engagement is envisioned by an organization — involved iterative consultations with four key service providers who were involved with YE at the local and national levels of the ACCESS OM project. The ongoing question through this analysis was ‘what organizes the work of these service providers?’ This process engaged me with the local and national YAC coordinators to explore the nature of their work from their standpoint.

To answer Question 3, I drew on the combined experiences from all participants and meeting observations to explore the ways that YE in this local context has impacted the development

and delivery of appropriate care. I discussed emergent findings with the YAC and Family/Caregivers Council at a meeting in early September 2017, then with service providers in the organization as preparation for a poster presentation in Fall 2017. The data collected began to reveal areas of impact at the individual level for youth advisors and service providers, and to a lesser degree on the operations of the organization and its relationship to the community it serves. The experiences relayed at these levels were both rich and evocative of how a small intervention can have significant impact upon the working lives of individuals in the organization.

Figure 2 below illustrates the data-gathering process to answer all the questions in the study. The texts constituting the practice discourse of YE were analyzed as a ruling relation upon the local work, and this analysis contributed to my growing understanding of how the informants' everyday actions were coordinated trans-locally.

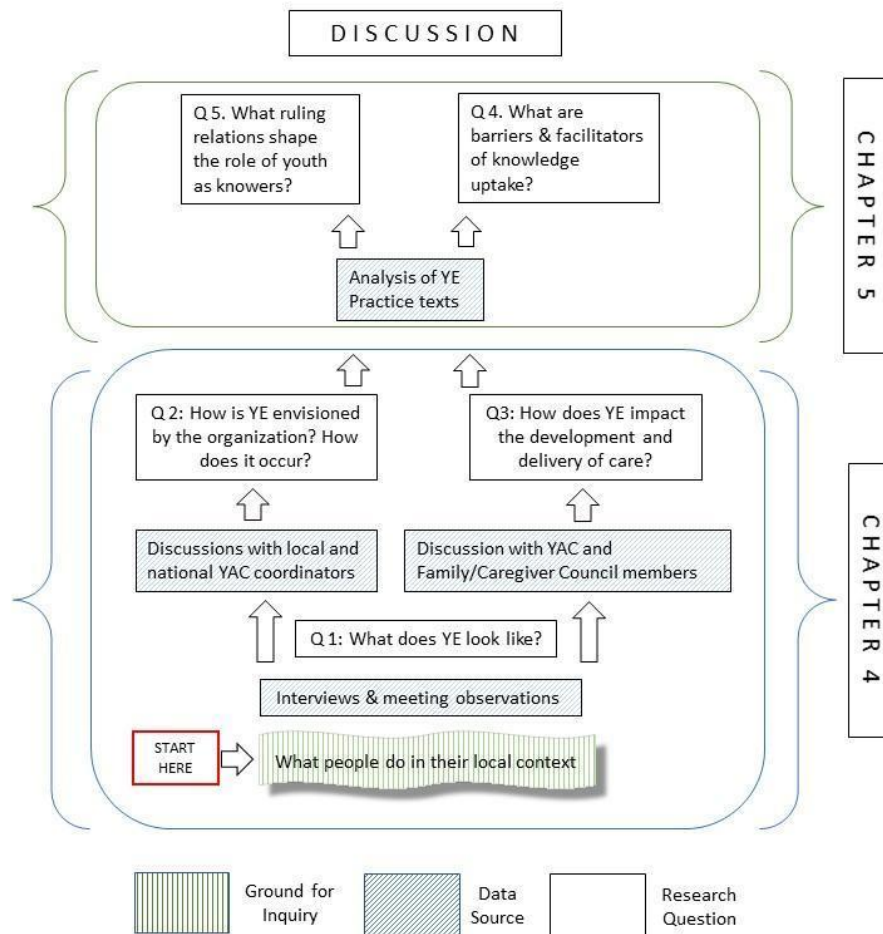


Figure 2: Data gathering process for questions 1 to 5.

Considerations for ethics.

Ethics approval (Appendix III) was secured from the Office of Research Ethics, on behalf of Western University’s Research Ethics Board; Protocol No. 108480. An additional level of ethics approval was secured at the research site, as a sub-study linked with the local organizational process of the ACCESS OM project. This approval was granted as Protocol No. 17FEB001 granted by the Chatham-Kent Health Alliance Ethics Board (Appendix IV).

Consent was sought and secured through Letters of Information and Consent appropriate to youth (Appendix V), adult participants (Appendix VI), and the parents of youth under age 16

(Appendix VII). The anonymity of all informants has been maintained through the use of pseudonyms assigned by me.

Rigour

Several considerations about methodological rigour in IE featured in the approach to the sampling, fieldwork and analysis in this project. Townsend (1996) notes that rigour in IE is established through its “theory and method” (p. 185), namely the transparent translation of its conceptual framework into the research design and analysis process. DeVault and McCoy (2001) state that rigour in IE “comes not from ascertaining a representative sample, but from employing the techniques in ways that explicate ruling relations” (p. 764). In this sense, rigour lies in the application of the IE lens to the process of seeking information within this context: the movement from what to whom, and back to what, in a manner that reveals how the experiences of people within the organization, the work that they do, is connected to relations outside themselves and their everyday functioning. This highlights a second consideration: the necessity of remaining grounded in people’s experiences as constitutive of rigour in IE. Smith (2006) states that “rigour comes not from technique — such as sampling or thematic analysis — but from the corrigibility of the developing map of social relations,” (p. 33).

As these relations became visible, and to ensure the ‘corrigibility’ of this map, I continued to “check” the account that was building by returning to the youth and adults who had informed it collectively, and grounding my findings in both their words in the transcript of their statements, and in further explorations through discussion when questions arose. These discussions, with three individual informants and with the YAC collectively, ensured that the findings were actually grounded in the data. Collectively, we built and presented a research poster on their engagement at an academic conference.

Finally, a last area of consideration regarding rigour has been in relationship to what other research paradigms and methodologies would refer to as objectivity. As Smith (2006) notes,

An IE does not rely on notions of objectivity in order to produce “validity”. However, it does strive to “produce accurate and faithful representations of how things actually work; it must be truthful. Political commitment here enforces the researcher’s

responsibility to get it right”. It must remain faithful to the accounts provided by people of their lived experience while going beyond that experience to explicate how that experience happened as it did. (p. 42)

In remaining explicit about my positionality through the conduct of this research, I aimed to describe my ‘political commitment’ and to explain how “the problematic” (Smith, 1987), “standpoint” (Smith, 2005; 2006), and “institutional capture” (Smith 2003) were essential tools in remaining faithful to the accounts provided by people, and in self-reflexive research.

This chapter has presented the methodology, strategy for self-reflection, and process of this study. In the following chapter, I will describe study findings.

Chapter 4

Chapter 4: Findings Part 1

In this chapter, I draw upon accounts provided by youth, engagement staff, service providers and administrators in order to answer the research questions in this study. The focus on their everyday experiences served to describe what YE looks like at this service organization, uncovering the nuanced dimensions in the work that adults do when tasked with YE in this context. From these experiences, the findings gradually trace up, one research question at a time, into an exploration of the relations of ruling that organize the work and impacts of youth engagement at the local service site, and upon the current design of mental health services. Through the process of tracing up, new data inputs were introduced, in keeping with the process of IE (Rankin, 2017).

Findings for Questions 1 to 3 have been organized in sections, according to each of the research questions (Questions 4 and 5 are answered in Chapter 5). Each section is complemented by a brief narrative that describes how concepts of the problematic, standpoint, and institutional capture served to advance the analysis.

Question 1: What does YE look like?

The experiences of YE shared throughout this study showed that engagement at this local site is comfortable and fun for the YAC members. It is also work for the adults. For everyone interviewed, it is extremely important that youth ‘feel’ engaged. Why such a feeling is important, and what engagement looks like, differs for youth and adult informants. The standpoint informants relayed drawing on various types of expertise and techniques so that youth would feel engaged in a particular way, often doing this work in the background or outside the time of specific YAC meetings. In keeping with IE’s generous conceptualization of work, the descriptions in this section point to the ‘workful’ character and skill of what the service providers do in this organization. The five types of work heard and observed through this study were: a) building comfort; b) scaffolding; c) creating transparency; d) listening; and, e) waiting. These will be described in more detail below.

Building comfort: “I want this to be a place they feel comfortable coming to.”

At this local site, the ongoing work of engagement was very pragmatically focused on recruitment and, as one service provider called it, “keeping youth at the table.” YE is an expected deliverable of the ACCESS OM research process, and those tasked with it approach it with professional commitment. Standpoint informants regularly presented information about the ACCESS Open Minds project and the YAC at community and school-based events in the area; they also communicated with other adults in and across youth-serving sectors, in order to find youth they could invite into the Council. Once youth were recruited, the standpoint informants worked to ensure that youth felt comfortable and able to contribute during their interactions with the organization.

Pam, who both recruited for and coordinated the YAC, as well as provided services to youth at the AOM site, described her work in YE as follows: “I want this to be a place where they feel comfortable coming to.” At YAC meetings, she used ice-breakers, art-based activities, brainstorming, debriefings of meetings, and multiple ways of soliciting feedback and providing opportunities for youth to contribute their ideas. She also ensured that there were snacks, fidget toys, colourful markers and materials, and a snow-cone machine in the meeting space for the YAC.

All youth in the YAC felt this sense of comfort and connected it to their ability to speak up during YAC meetings. Sandra, who joined the Council when she was 15 years old, described her first experience of engagement as follows:

That first meeting, we were all sitting in a conference room ... It was all shyly passing around food and drinks, and nobody talking very loudly. It was all “Raise your hand if you have this idea” and eventually we got into group settings and started to do some planning ideas of what we thought colour schemes should be, or something like that, but it was ... very hypothetical two years ago. Now, myself along with another youth have been given the role of co-chairs. So it's completely youth-led now. It used to be someone starting us off, and we'd provide feedback. And it's a lot less formal. Now we just sit at a table. We drink coffee or have cookies or whatever, and we're just throwing ideas. The time passes so fast because we're getting so much planning done with every meeting.

Comfortable enough to speak up.

For Sandra, feeling comfortable and welcome was a prerequisite to being able to participate. Her sense that the meetings were ‘youth-led’ linked to that sense of comfort. For Max, another YAC member, he felt welcomed by the friendliness and easy flow of conversation at the YAC meetings. The comfort he felt at his first meeting contrasted with the intimidation he had anticipated. He said:

Once I got here and I saw a familiar face ... Once we all sat down and started talking, right away I felt comfortable. There is no judgment. They made me comfortable right away, so it didn’t have that intimidation factor that I thought I would.

The informants also built comfort intentionally by using techniques that encouraged youth to provide input at their own pace. Pam said: “Probably more of the work that goes into the Youth [Advisory] Council is the more recent, and sometimes the more fresh, youth that come to the table. [They] may not have been speaking openly or sharing ideas, so [the work is] really trying to be creative with how to engage them without centering them out.” In my observations of YAC meetings, it became clear that Pam would create multiple points of entry for youths’ questions and ideas. She returned to points raised in previous meetings, or early on in the agenda, stressing to youth that if they came up with more answers, or formulated a different answer to what they had said before, it was perfectly fine to return to that point and discuss it again. This way of returning to a previous point was recognized by the YAC members as a way of having less professional and formal agendas, which made it easier for youth to participate. Lloyd described the effect of Pam’s approach to the meetings as follows: “It’s making it so that the discussions are not a done deal. They’re not finished. It’s like having the ability to bring back other conversations if we need to.” The possibility of not knowing what to say in a given moment, but having the opportunity to come back and share what you think once you do know, was a factor in common to the youths’ experiences of comfort.

All informants indicated that some YAC members will not say much when they first join the Council. A quiet presence was seen as an acceptable way of participating in the group, even by other, more vocal YAC members. Sandra and Lloyd, who as more senior YAC members now co-lead the Council, felt that this was part of the intentional approach that made people

in the Council feel comfortable. Sandra described this as “not being pushy” and being “respectful.”

Comfort in relationship to fun.

While describing both the feelings of the youth, and the work that adults do towards it, the language of *building comfort* began to reveal the nature of the work as an epistemic process. It was in relationship to these feelings of comfort, and that their input was welcome, that YAC members associated their engagement in the Council with fun. “Fun Nights” became the name of their one regular outreach activity in the community, in which they invited other youth to do things in the hub space, such as watching movies, making crafts or playing board games. The term ‘fun’ was also used by some adult service providers in relation to their involvement at YAC meetings. For example, Lynn said:

I think the youth council is just fun ... It’s exciting and being creative with the youth is great. Sometimes it’s boring and just discussing and agreeing on things that have already been — they even come from above my head and other people’s. But a lot of the time the YAC is just fun, just getting together and being creative with other people.

As a standpoint informant, Lynn stresses the connection between fun and creating with the youth. She then contrasts it to the boring (i.e., disengaging) experience of discussing aspects of the organization that she and the youth have no access to, in either understanding or decision-making power. Lynn’s comment acknowledges the organization as a context where YE develops.

Creating transparency: “So they know what to expect.”

All adult informants described their intentional efforts, and displayed skill in, preparing youth to interact with the organization or the system in different ways. Pam and Lynn described briefing new YAC members before their involvement in other meetings in the organization or outside of it. This preparation included explaining to youth what meetings would be like, who would be there, walking through the agendas beforehand. Pam did this work, as she put it, “so they know what to expect.” All standpoint informants noted that it’s a priority for them that youth know what’s going on within the ACCESS OM Project,

including what meetings will be like. They all assumed that these sorts of meetings would be new to youth, and that they would need the support to understand how things work in the organization and in the system in general.

Understanding the context in advance.

In some cases, as noted above in the words of Lynn, the standpoint informants felt that they did not know or understand themselves how some decisions are made at higher levels of the organization. Lynn described these decisions as “above my head,” denoting the scope of her own role, and her limited access to certain kinds of organizational knowledge. In this sense, Lynn identified with the youth as a person excluded from the knowledge processes that shape service delivery.

The effort in building transparency mattered a lot to the YAC members interviewed. They saw a direct relationship between feeling knowledgeable and feeling engaged. Lloyd described the quality of his engagement in this way: “[YAC coordinator] has been really great with engaging the youth because we know what’s going on with the project and we’re actually contributing to the project.” Max described how knowing what to expect made it possible for him to imagine himself as a member of the Council:

Again, put it down to knowledge ... It helps to know what it will be like. Here’s this place: this is exactly what we’re about. When you come here, this is what it will be like, this is who you will speak to. Like when I saw [YAC Coordinator] at that first meeting, and meeting her showed me what it would be like to come here.

Understanding the system.

Service providers also brought the youth advisors to meetings and conferences in the community and outside of the local setting, at the level of provincial and national service-planning. Sandra attended a conference in Toronto alongside site administrators. She did not speak publicly or have a role as a YAC member at this event, but was invited, as she put it, “So I would get the long-range view.” Lloyd and Peter also attended conferences and service-research and design meetings outside of their local contexts, in their capacities as YAC members. For Peter, his sense that he was meaningfully engaged was connected to the encouragement he was receiving from adult providers to contribute at this level. He said:

To have that support ... That someone believes in something you can do, that you might not feel you can do. It's really powerful. Even being able to say yes to those situations, even when they scare you ...I probably wouldn't have done any of these things if I hadn't had these little nudges.

Understanding how the organization operates.

YAC members' ability to understand the content of meetings within the local organization directly impacted whether they could contribute and, in turn, whether they could feel engaged and valued. In relaying his experiences of Facilities working group meetings during the time that the lease negotiations were the primary focus of the discussions, Lloyd said: "I didn't feel very valued as much, because it was something I really couldn't contribute to."

The adult informants described many instances of working to make decisions and processes in the organization transparent to youth in order to facilitate youths' contributions as advisors. Lynn, who both worked with youth as a Peer Navigator and also attended YAC meetings as a supporter, described the careful way she would bring her perspective to the YAC discussions, explaining her everyday work, to contribute to the YAC members' brainstorming on ideas for the space design. She described a discussion with the YAC members relating the design of the office space in the Hub. The idea of creating different themes for the consultation rooms in the Hub had come up, and the YAC members had proposed a beach theme, complete with beach chairs, for one of the rooms.

From my view, I can think of what happens, like "What does our desk need to look like? What are some safety concerns?" You wouldn't know unless you actually worked here. But it's still, you know, having both sides and coming together, based on: "This is what I think based on how I work."

As Lynn suggested, being transparent included explaining the experiences of care providers so that youths' input could be meaningful to the context. Lynn added:

I think it's just important to be transparent, and honest and open about things. So if this isn't going to work, it's not because we're not listening to the youth, and just always being open, I think that's really important in what we do.

Lynn and Pam often found themselves translating the realities and language of the work of the organization — and more broadly of the institution of mental healthcare — into more understandable terms. For example, they consistently spelled out acronyms during YAC meetings, and gave background information on places and people whenever new youth members joined the group.

Transparency as a means to create shared expectations.

Standpoint informants in administration roles also worked to create transparency for the YAC members. They spoke about the need to give youth an understanding of the organization as an element of genuine engagement, and a responsibility of the adults' roles, so that youths' input could be meaningful. Rose, an administrator, said:

I think it goes back to how we create shared expectations, so we don't set up people asking for the moon when that's just not a reality. And we don't want them to be disappointed or think that some major brainstorming or great idea fell on deaf ears. But if they know what the realities are to start with, that means they're brainstorming within that realm.

Demarcating what was feasible often involved explanations of the budget or the nature of service-provision in the community in order to make transparent why something could or could not change. For example, during the sessions that focused on choosing a physical space for the Hub, Rose explained to the YAC members that choosing a certain space over another would have repercussions on how many full-time positions could be hired to serve youth in the area. The work involved listening and reflecting back what the YAC members had stated they wanted, then working to make it feasible within the culture of cutbacks and risk adversity.

Rose felt time spent creating transparency was well spent. She said that a failure to support youth in understanding these realities can have adverse consequences, because youths' demands are perceived as unreasonable or militant by other stakeholders. She explained:

It's a problem and [the youth] quickly lose credibility. And that's where I think the project has taken a few miss-steps. It's when that type of messaging is happening and

a bunch of people start tuning them out and not seeing the value of having youth there. It's really making sure that you're working together closely to establish what the message is and the delivery of the message. I think that's an important piece of why the youth need to be on every single working group and council. I think that they start understanding that you can't have grand plans and not have any ability to execute them. Otherwise they just become great ideas.

Rose's approach as part of her leadership role within the organization is to support the presence of YAC members in as many working groups as possible, in order to increase their familiarity with how the service site operates. Her efforts to create transparency by explaining things to youth, and installing YAC members in working groups, were in keeping with her professional role in the administration and decision-making in the organization. Rose's work of YE is similar in nature, though different in content, from Lynn's work. Lynn can only clarify things to the YAC members as far as her role allows, for example relating the details of consulting with youth who seek Peer Navigator services. At the same time, both informants are performing the same YE work of including the youth in the knowledge processes of the organization by giving them the knowledge resources to provide their perspectives in a meaningful way.

Scaffolding: "What do you want to discuss?"

The use of scaffolding techniques on the part of service providers emerged as a third type of intentional, skilled doing that supported youth to contribute their perspectives. I employ the term scaffolding here in reference to a "deliberate informal instruction in the context of socialization," (Gauvain, 2005, p. 129), or as a "process that enables a child or novice to solve a problem, carry out a task or achieve a goal which would be beyond his [sic] unassisted efforts," (Wood, Bruner, & Ross, 1976, p. 90). In performing this type of scaffolding, adult service-providers created supportive structures within the progress of a meeting so that youths' perspectives could be articulated and heard by others. This work became evident through observation of meetings. For example, in a meeting of the Facilities Planning Group, Pam and Rose, both at different levels of leadership in the organization, interjected in the discussion and slowed down the meeting in order to set up a question that engaged the views of a YA in attendance. Once the youth shared their opinions, Pam asked a

probing question to encourage the youth to describe further what they meant, and Rose commented on the YA's insights, elaborating the point. Rose then invited others to engage with the points made. In doing this, both adults were scaffolding the YAC members' input, going against the grain of a fast-paced agenda to create the conditions where a young person could articulate their ideas. By elaborating on the discussion, and engaging others with it, they worked to embed the youth's perspective amidst the thinking of others attending the meeting, including hospital administrators and community stakeholders. It is notable that Rose was chairing this meeting, because she had the authority to set the pace of the discussion.

Scaffolding for youth to understand what matters to them.

Similarly, Pam created scaffolds for YAC members to provide their perspectives in meetings of the Council. She provided guidance in how meeting agendas were developed, enabling youth to define the content of the agendas themselves. She also facilitated brainstorming sessions to develop initiatives that the YAC was undertaking, collaborations with others (such as a Pinterest-based group brainstorm define the AOM name and interior design for the Hub space). Pam described that her role in the YAC meetings was about encouraging the youth. At one meeting of the YAC, she said: "You can steer the boat in any direction you want to go, if you're feeling that this isn't really a priority right now, we don't need to discuss it." This ability for the YAC members to choose what they wanted to talk about at their meeting also meant that Pam had to give up including items that her role or current task load required her to address. She said: "I'm trying to empower them to see what their priority will be."

This type of scaffolding was also apparent in the process of developing a YAC newsletter. The decision to put together a regular publication had been made at a previous YAC meeting. Pam started the meeting by asking the YAC members about electronic newsletters they were familiar with, and soliciting ideas on an online platform that may help in the design process. She then gave the meeting over to YAC member Peter, who had design expertise, and he led a conversation on what was possible with the templates and software he uses, and what people wanted to see in the publication. Pam stepped in again at this point, and asked the youth which of them would contribute to content creation for the specific pieces listed, as

well as when, effectively playing a project-management role to the process that the youth had devised together. In doing so, Pam scaffolded the creation of the newsletter by installing specific resources and processes towards its development, without contributing to its content. It is notable that her scaffolding included time and support over an output that she would not be able to deliver on herself, since the newsletter production resided entirely on the YAC members. YE in this instance looked like capacity-building of youth so that they could generate their own content and share their perspectives at a broader level, beyond their interactions with the adult service providers locally.

Shutting off the professional realities: “To genuinely listen to youth.”

Adult informants saw the intrinsic value of listening as part of engagement, and recognized a tension stemming from genuine listening. In describing how they listen, they pointed out active ways that they ‘shut off’ their professional and organizational knowledge, as a requisite to keeping an open mind. Pam described this tension as follows:

And I really try not to have that background voice come to the forefront because I think that’s where we can get into our tunnel vision and continue to do as we are used to doing. So it’s really an open conversation. There have been times when we have said, ‘We’ll have to look at the budget ... Let’s look at the ideas we have, while keeping in mind that we only have so much to spend, so ...’

A similar view was expressed by Fran, relating her work as a Peer Navigator. She said: “You have to shut off the professional realities side, in order to genuinely listen to youth.” Lynn, also a Peer Navigator, described the kind of listening she does with the YAC as something she brought into her work as a service provider:

It’s important to me, not having pre-conceived notions. Sometimes I’ll have these case notes come in and have a referral and it seems very overwhelming. And I think “How am I going to help this person? What am I going to do? Where am I going to connect them?” And then just kind of being like it doesn’t matter, just meet with them and go from there. And it’s about them — it’s not about you!

For the service providers, the commitment to remain open-minded was an important feature of their experience. All adults interviewed stated that their interactions with the YAC members were rewarding because they bring creativity and optimism to their work. At the same time, they saw that their work entails negotiating the tension between what was proposed by youth, and what was possible within the organizational realities.

Rose explained how she worked with this tension in relation to the funding of the Hub space, which came into question soon after a change of leadership at the hospital that administers the service site. Although the YAC members had spent months brainstorming and collaborating with others to create a youth-friendly space, its realization was delayed, and even threatened, by the hospital's change in leadership. Rose said:

When an organization — it's kind of that Maslow's thing — when an organization is just trying to pay their bills, they're not into the best ... the most ideal thing ... this fantastic youth Hub model. They're just not there. When you're actually trying to do core services and meet the budget and reduce staff impact. Then you don't get to do the great, wonderful things that we all aspire and want to get to.

Despite this tension, the YAC members interviewed reported that they felt heard by the adult service providers. This listening was a crucial part of YE for the youth. Peter said:

A lot of engagement is putting the issues on the table: yes, and even things that the doctor may not think of. Or people here. Because a lot of them are not in their 20s. They are older and they don't have that viewpoint. It's things that they would overlook.

The continuous work on the part of Rose, Pam and Lynn to make things transparent meant that, even when their ideas were not taken up because of organizational realities, they felt their input was valued. Lloyd said:

There were certain ideas that even you and I would know that they probably wouldn't work ... So I think, as far as reasonable ideas go, I don't think I've ever had a problem with that ... One of the ideas for example, someone said that we should use the pool, but after everyone talked about it, it was going to be really expensive, and we just,

wouldn't have it in the funding to do, and we wanted to spend that amount on other things.

Waiting work: “A little bit of a pause.”

The experiences of informants also revealed that YE involves working with the slow pace of change of the organization. At this research site, the initial recruitment of the YAC took place in 2015, but it took until summer of 2018 for the Youth Hub space to open, and for the YAC members to see their initial designs for a youth-friendly space become reality. Related to the change of leadership at the host hospital described, there was also a delay in the lease agreement for the Youth Wellness Hub location. As a result, the organization provided an interim space for the Hub to start operations, and the YAC met and continued its activities in this provisional space through the waiting period. The visibility created by a strong youth and family presence meant that the host hospital, as well as other funders that ultimately have contributed to the sustainability of the model, had an increased sense of ownership and accountability for the project. The YAC members were busy during this waiting period. Their activities at the start of the project, prior to my data-gathering phase, had included giving input into the hiring of the Peer Navigator, contributing to the national ACCESS project name (brainstorming and proposing the “Open Minds” component), and creating the interior-design concept of the Hub. Then a long waiting period began that included lease negotiations, as well as a change of leadership and fiscal culture within the hospital. Pam described this period as challenging because it meant keeping the YAC members engaged “when there is not much happening”. She added: “There is the danger of disengagement if youth don’t have time to communicate with each other or share communications.” At the same time, some of the YAC members, as is appropriate to that age group, were dealing with life changes that took them out of the community, often into post-secondary schooling in other towns.

For the standpoint informants, the constant awareness of project timelines and sustainability issues shaped their professional work, alongside the need to sustain the numbers and enthusiasm of the YAC. In Rose’s view, the waiting work at this service site played a critical role in ensuring that the Hub became a reality. During the waiting period, the ongoing

activities of both the YAC and its coordinator and of the local Family Caregivers Council kept the project visible to the community stakeholders and hospital leadership. Rose said:

So that's, fortunately, the hospital in the transition saw the value, and fortunately we're starting to demonstrate the value. I think that was very important as well.

Because if we'd even just started up, I think it would've been easy to say "this isn't a priority." But we'd already established a presence, we had so much community buy-in, I think that it demonstrated the value. ... I think that speaks a lot for the ACCESS model and how it's already made and created an influence throughout the community.

Through this time of waiting, the YAC coordinator found herself giving YAC members repetitive updates about the lease negotiations, and grew concerned about keeping youth engaged. In response, she stepped back in her role, and began supporting to YAC members to lead the Council. They devised a lot of activities together, including the design of the green space around the proposed service site, a nomination of one of their members for a community award, and the creation of "Fun Nights".

The waiting work allowed YAC members to develop communication skills. They created recruitment and communication materials, and gave presentations in the community to share knowledge about the ACCESS OM project and the Youth Hub. The newsletter was about ensuring that families, community donors, school administrators and other community service providers heard what the YAC members had to say. These activities were 'waiting work' in that they may not have happened if there had not been a period of time waiting for the establishment of the permanent Hub. Through them, the YAC members developed trust and familiarity with organizational processes, strengthened relationships, built capacities and skills, and participated as advisors and advocates in other contexts. At the community level, these activities underscored the urgency and scope of youths' concerns to decision-making and funding bodies, such as the hospital board and the Rotary Club.

Synthesis: Chasing a Feeling versus Actually Making Change.

I close this section with a discussion of how these findings shifted the initial problematic shaping this study, an incident common in the development of an IE. A research problematic begins "with the everyday events in people's lives, and in their problems of knowing —

being told one thing, but in fact knowing otherwise on the basis of personal experience,” (G. W. Smith, 1995, p. 21). The problematic is generated from the data, and it often rests on accounts from the informants that reveal troubled or conflicting relationships between the authorized account of what is going on, and the experiential knowledge of it. The tensions that the standpoint informants know about and experience are either invisible or misrepresented (Rankin 2017b).

The original problematic driving this investigation was the concern that service providers and organizations in general were being mandated to engage youth in the absence of resources and operational clarity. My concern was that such mandates could lead to the implementation of faulty, tokenistic or merely decorative YE processes that do not lead to youth-centred improvements in the system of care.

In this particular organization and systems-improvement project, two areas were clear from the outset: 1) The local setting relied heavily on the Y-PAR and YE discourse promulgated by the National ACCESS OM project, and reinforced through its National Youth Council and its yearly Network activities; and, 2) The goal of YE was expressly to include the perspectives of young people into service design and delivery in order to transform mental health services (ACCESS Open Minds, 2017).

The local experiences described above show that adult service providers put effort, time, affect and diverse resources in the service of engagement. Youth engagement, as described by all youth informants, consisted of a welcoming, comfortable atmosphere with friendly people and lots of choices. When asked to further describe what ‘engaging’ meant, the YAC members used the phrases “less formal,” “feeling heard” and “giving everyone lots of opportunities to talk”. They also indicated that they felt valued by the organization because they could contribute to the conversations there, and called this ‘genuine engagement’.

The standpoint informants spoke about fun and creativity as core characteristics of the type of YE they sought to generate, and conveyed a consistent preoccupation with sustaining the YAC members’ interest. Their descriptions and my observations revealed that the adult informants’ work involved continuously negotiating potential barriers to youth feeling welcome and valued as YAC members. They built opportunities for youth to develop and

share their opinions, to understand the organization and system, and to develop a distinct role in the community.

The standpoint informants' YE work sometimes went against the grain of the pace, efficiency and professional roles of the organization. Nonetheless, in performing this work they increased youths' competence to act within the professional culture of the organization, and made friendlier features of that context that had resulted in intimidation or exclusion for YAC members in the past. The findings in this section suggest that YE in this local site was primarily knowledge work. In nuanced and intentional ways, what the standpoint informants do served to increase youths' epistemic resources and credibility within the context of the organization.

As I reflected on the nature of this work, the problematic evolved. I began to see a dissonance between the fun, the work, and the impact that these two things had upon the YAC members. The recurring concern with fun and positivity spoken by the adults, and the concern that youth stay engaged in high numbers, signaled the appearance of ruling relations. It flagged my attention to the impetus for YE evident in the national project, and in particular the kinds of manuals and texts that the service providers were using to learn about YE. In contrast to that 'fun', both the interviews and meeting observations showed continuous concern on 'what youth know' in ways that set the adults to work *against the stream* of their own practice and context. Additionally, the knowledge work taking place was familiarizing the youth with the way the organization operates, so that I began to consider how such familiarity with the organization would dilute the diversity of the youths' perspectives. This was the risk of institutional capture.

My fieldwork had revealed a YAC that had been recruited two years previously and, though in lesser numbers, still maintained a level of regular and enthusiastic engagement while waiting for the Hub space lease to resolve. The standpoint informants were concerned with maintaining these numbers. In response, they used the time to engage the YAC members in various activities that were fun and built their capacity to interact with the organization, the community and the broader mental health service sector. In doing so, they may have unintentionally promoted the institutional capture of youth, training and steering the YAC to speak the same language as the organization, align with the dominant view, and avoid any

actual collisions or pressures upon the service site or the system itself. With these concerns in mind, I proceeded to explore the work of the adult informants by asking how YE is envisioned by the organization, as well as how it actually occurs.

Question 2: The vision of Youth Engagement versus How It Occurs

The adult informants, because they were tasked with engagement activities, hold a distinct standpoint. Their standpoint includes not only what YE feels and looks like for them in the day-to-day, but also how YE unfolds in relation to their individual professional roles within the organization, and to ruling relations that organize their work trans-locally. Their standpoint has the ability to encompass these multiple, and often competing, vantage points of the situation of engagement. In keeping with the focus on how people's everyday experiences are organized by relations outside of their reach, the findings in this section include 'tracing up' — a technique particular to IE (Campbell, 2006; Smith, 2006). This tracing up was accomplished by engaging Maria, the coordinator of the National Youth Advisory Council in ACCESS OM, as an informant and collaborator in an integrated knowledge translation (IKT) process. Together with the local YAC coordinator and Maria, we discussed and reflected upon the findings presented in Section 1 and considered how their work in YE unfolds. These conversations resulted in the creation of a conference poster and presentation, and provided further data that will be shared in the section that follows.

A youth-centred values orientation: "I aspire to authentic engagement."

When asked how they felt that the organization envisions engagement, the service providers interviewed had a very clear sense of the value system that informs their work. Pam and Lynn referenced values of collaboration and authenticity and, with Maria, described the ACCESS OM core values. They expressed an ongoing concern with, as Maria put it, "being able to deliver on these values" in their work with the YAC members, even beyond the moments of interacting with them.

At the same time, these informants resisted the idea of 'transformative' engagement when I asked them if that's how they would define the focus of their work. The framing of engagement as transformative stemmed from the 'system transformation' language surrounding the national ACCESS OM project, though the project itself does not

conceptualize engagement as transformative. Similarly, for the informants, the notion of transformation as a direct result of youth engagement was too large a goal, even though they felt that YE has the potential to make change within the system. Maria, who coordinates the National Youth Council on the overall project, said:

I aspire to genuine or authentic engagement. 'Transformative' would mean speaking to its effect in the context, and that takes longer to achieve or document at this point. I aspire to authentic engagement by working with young people and tracking how we're working together.

In explaining what she meant by 'authentic', Maria said: "To update is not engagement. Sometimes you have to revise, undo, re-invent how things work because you see that the trajectory it took you on is not YE." Maria realized her commitment to being youth-centred through her efforts to track, reflect and remain flexible in how she works with youth.

At the local level, Pam also resisted the idea of transformative engagement as the goal of her role. She said: "'Collaboratively alongside the youth' that has been something we continue to strive for here ... For me, to just update the youth [on how the project is going] is hardly engagement at all, even when they provide input and feedback." Pam's work practice involved keeping youths' priorities and capacities 'front and centre' to be able to do more than update the YAC about activities already going in the service site.

This youth-centred orientation was also described at the administrative level of the service site. Rose said:

I use the analogy of how at the gym celebration, how once the kids' functions were done, the gym started clearing out. And that reminds me of who are the people gaining the attention, at the centre of this community: it's the youth and families.

Rose's comment underscores that the presence of youth and their families concretized a youth-centred orientation, which she then seeks to apply in her own sphere of influence within the organization. Similarly, Maria and Pam's response to the word 'transformative' revealed their commitment to work on, and be accountable to, what lies within their power.

YE is not always codifiable as work: “Our roles are not at ease.”

When they spoke of keeping youth front and centre, the adult informants described a focus on process, rather than outcomes. For example, the work towards YAC members’ feeling of comfort with the organization, and the potential for them to ‘come back to the table,’ are grounded on the continual development of youths’ capacities and interests in relation to the project. What they do with the youth changes in response to the YAC members needs and capacities, as exemplified by Pam’s encouragement of “You can steer the boat in any direction you want to go.” As a result, the activities and their outcomes of YE are not planned or strategized formally, beyond the category of ‘youth engagement’.

The informants described the tension between this approach and how such an open or responsive process might be perceived in terms of professional work. They feel the difference between how work is codified in the service-delivery setting, and how it needs to occur in order to engage genuinely with the YAC members. Maria says: “Constant change can look like failure from a professional-performance side.”

A lack of change can also bring into question the work. Maria said: “National members will be working on the same thing for a long time, and updates to executives or boards will be repetitive, so that brings to question the work sometimes.” Pam echoed this experience: “As an adult professional, it is uncomfortable to feel like there is nothing new to report. It looks like no work is happening because there is nothing reportable.”

Similarly, while a drop in the number of youth engaged can look like a failure of YE efforts, Pam explained that lower numbers don’t necessarily signal a lack of engagement:

Summer time at [the service site] was a decrease in numbers, where things felt not as successful. Feeling lower. But as communication started to happen, the conversation was really organic and genuine, and we saw the momentum in the Council. Over time seeing the fluctuation in numbers can make you question the success of your work. It can feel like a shift. But the nature of the work is about shifts and flexibility — that’s a value.

These comments reveal an expectation that YE be delivered, even while its precise activities remain outside the organization's conventional way of operating, and are not articulated clearly in the resources that describe how to do YE. Services providers tasked with engagement feel how their work does not align with the organizational notions of what is professional, plannable and codifiable work. "Our roles are not at ease," Maria says. "It involves becoming comfortable with things developing organically."

This tension is negotiated in practice through the ways that the informants track their work and evaluate its effectiveness, both in terms of their interactions with youth and interactions with others in the organization on behalf of the YAC members and activities. Pam said: "We measure success with numbers and we need to redefine what success looks like — what [the YAC members] give to the project and what the project gives them." Maria added: "How to measure success as a council? It's highly individual to each council. Is it drop out numbers, skills development? How we observe their participation changing? Their interests changing?" These approaches to evaluation of their work, and of the youth councils in general, are creative and distinct from the conventional work in the organization.

As the informants described, the lack of an appropriate and established way of evaluating their work is a challenge, but they also see it as par for the course in a participatory approach that has not yet developed guiding literature. They saw this knowledge gap as an opportunity to enact guiding values. For example, the indeterminate quality of some processes prompted ongoing reflexivity, and the need to constantly consult the YAC members and others in the team. Maria said: "This is a shift in culture for the whole organization and model. Our roles are so dependent on our re-evaluation, and we're called to task much quicker in our rapport with young people, so it is crucial to re-evaluate."

In administrative-leadership roles, the flexibility and process-orientation of YE requires a way of working that runs counter to previous models of administration. Rose described the need to be flexible on the kinds of roles that support a youth-centred orientation, which includes the part-time position of YAC coordinator. She described how YE became a formal feature of the service site through these roles:

I think [it happened] through the creation of some of the actual roles that we have. So, through the youth advisor role and the family advisor role, I think that they are actually ... again, it's fantastic because they are demonstrating their value in spades. I mean, right now if I receive any extra money, even in any other program, I'm starting to look at ... even in our addictions program that is not related to ACCESS, I think that we need a family advisory role.

The experiences relayed by these informants show alignment between how the organization envisions engagement — as a youth-centred orientation — and the way YE occurs in the context through the work that they do. In describing their practice, the informants articulate how working in a youth-centred manner involves values-based behaviors of collaboration, flexibility, reflexivity and close connection to youths' evolving capacities and circumstances. For these adult professionals, this mode of work sometimes requires negotiation and unease with, as well as innovation of the way their roles have conventionally functioned in the organization. These negotiations are associated with increased inputs of youths' perspectives in the processes of the service-delivery site.

YE and professionalization: “The risk is that the message does change.”

The adult informants described negotiating a balance between conditions that empower youth within the organization, and the risk that young people become ‘professionalized’. The concept of professionalization is derived from sociology and suggests the establishment of a boundary around the roles and expertise that an individual can provide to a given context (Meyer & Tarrow, 1998). Professionalization is similar to the IE concept of institutional capture (DeVault & McCoy, 2002; Smith 2003b) as it relates the way perspectives become limited to a particular way of acting and thinking. In the case of ‘professionalized’ youth advisors, perspectives would be limited by nature of their prolonged exposure to organizational language and ways of operating, so that youth begin to echo their context rather than provide knowledge from their diverse lived experience, and that reflects the needs of youth who are outside the system of care. Institutional capture takes this concept further to reflect a cognitive capture: in that case, youth would ‘see’ the world with the lens of the institution, and think only within those terms.

As described above, much of the work that adult informants do towards YE relates to building youths' knowledge resources and capacity. Rose described this type of capacity building as a responsibility of the adults in the organization, and a requisite of genuine collaboration:

You can definitely do more harm than good if you're bringing youth in and engaging them in what's meant to be a healthcare business, and not helping them to understand the variables, how to weigh them, and how to navigate around some of them ... Bringing youth in and co-creating and working side by side isn't meaning you hand everything over them. We're responsible in making sure that we guide them, and do the coaching that helps them.

Professionalization can also occur passively. At this service site, the pace of organization and lease timelines gave the YAC members time to get very familiar with the culture and language of the organization. Pam said:

I think with our youth representatives, they have participated in several different committees and they represent on the national council as well, so they're very familiar with how the meetings have run, and they're able to give some feedback on what they feel has worked and how they can improve. They've been kind of involved from the beginning and have seen different committees in operation so they have things to compare to.

The danger of this approach is that, rather than soliciting youths' input because of the vantage point that their lived experiences provide, their value as advisors rests on their familiarity with organizational processes. This approach both negates the original aim of their advisory role as *an outside perspective*, and precludes from participation any youth who have not had professionalizing experiences, or who hold views that are dissonant with the organization. This nuance in the work of engagement raised concerns relating the pressure that service providers, and organizations, receive to engage youth, and the possibility that such pressures lead to consultation with limited numbers of youth, namely those who are adept at attending meetings.

Further, Pam's comment suggests that the more meetings a young person attempts, the more able they are to provide feedback on how the meetings should be run. Such a view illustrates that the danger of professionalization is not only on the youth advisors themselves, but on the way that YE is conceptualized. Pam's role as coordinator of YE means that she is responsible for keeping a certain number of youth at the YAC table, and for involving these youth in other meetings within the organization. Pam's comment reveals how the scope of her role demarcates what she sees possible as the scope of youths' input. As long as she's primarily tasked with holding youth-friendly meetings, she will concern herself with whether youth consider other meetings in the organization sufficiently youth friendly. The content of such meetings, and whether youths' input then made a difference in the decisions taken by that particular group, is less important to Pam because it exceeds the scope of her own professional role.

Maria described a parallel situation relating the potential of professionalization with the National Youth Council, who also found themselves with some waiting time while the Ethics Review and other processes unfolded. Maria said: "What we did while waiting was about learning to participate, advocate, communicate in ways most accessible to their audience. The risk is that the message does change. That's worth monitoring, but it's not evident in this group." Her way of monitoring, as she described it, was to keep checking with the youths' message to reflect what they felt mattered to them, even if the language that they used to describe it changed over time.

Rose saw this dimension of the adults' responsibility as a matter of helping youth to articulate what they feel in 'audience-appropriate ways'. She says:

[It's about] making sure that they're learning how the decision-making goes, and the importance of weighing options, and the importance of pitching ideas that are palatable to all different people. And that's, you know, it's their idea, but there's also the importance of delivering a message that. Asking them to reflect: 'Who is your audience?' Right? You have to change how your language is, and you have to help model ways for emerging youth. And that's not meaning to change their messaging. Rather, all of us are responsible for the delivery of the message is right, to the individuals who are listening, and who are our intended audience of the message.

By focusing their attention on youths' 'message', both Maria and Rose acknowledge that the YAC members' growing language and organizational competencies make them vulnerable to capture by the institutional ways of thinking. They express a commitment to be vigilant that the youths' message does not simply become an echo of the organizational view. Rose, whose role involves communication with organizational leadership and external stakeholders, is focused on making the youths' message understandable, even 'palatable', to others.

On the other hand, and in keeping with her professional role, Maria's focus is on supporting ongoing engagement and communication between the YAC members and the organization. Maria acknowledges that youth will absorb the language and practices of the adults; in striving for 'genuine' engagement, her vigilance centres on making sure the youths' message is truly theirs. She works to build this into the structure and processes of the YAC, in the way that meetings are facilitated, and in the encouragement for youth to develop leadership within the project. Maria adds: "The thing to remember is that they've been set up as a community of practice for youth involved in the project because of their lived experience. They are not functioning as a professional board." She described how, at the National and local levels, the youth advisory councils provide youth representatives to various adult-led committees, but the YAC members develop and retain their own working culture by creating their own terms of reference, ways of operating, and driving values. This distinction is an explicit, instituted mechanism to support YAC members acting as youth, not professionals, with the national project and the organization.

Championing from different levels: "You need leadership to buy in."

At the level of coordination, YE is envisioned and practiced as a constant championing of a youth-centred orientation. Maria and Pam expressed the importance of formalizing the role of YAC coordinator in a written communication through the process of writing an article about their roles: "Our position is that genuine engagement is supported by dedicating a professional position to do that administrative and relational work of engagement, linking to the youth." This view was also supported by Rose, who envisions the coordination of YE activities in the local context as a 0.5 full-time employee (FTE). Beyond funding these positions, the kinds of personnel hired, and the professional development and management support that they receive to do their job, also makes a big difference upon the quality of YE.

Maria says: “You need leadership to buy in, in order to fund engagement and the roles that support it; and to share outcomes from engagement, which are sometimes harder to translate in the conventional research/programming reports.”

Particular soft and relational skills are required to be sensitive to youths’ growing capacities and interests, and to generate consistently positive interactions. Both YAC coordinators interviewed are trained in counselling and social work, and hold skillsets geared to building and sustaining trust, working with diverse communication styles, and building therapeutic alliances even in non-therapeutic settings. In employing these skills, the service providers are able to recalibrate what works and doesn’t work to ensure that their activities stay aligned to these values of authenticity, collaboration and loyalty to youths’ priorities.

An important element of that authenticity, for the two coordinators interviewed, is ensuring that they do not speak for the youth, but instead create the conditions for youth themselves to speak up. As noted in Section 1, both youth and service-provider informants described the importance of youth feeling that they can fit in and contribute during their interactions with the organization. This was observable in Pam’s conduct at the YAC meetings, where she would gently ask for input and calmly hold her silence while YAC members worked to articulate their views; if no one had anything to say, Pam moved on to other points just as gently, and circled around to earlier questions to provide entry points for the youth continuously and without pressure. This is a fine balance to hold, because youth are just as likely to disengage if the expectation is too low as if it is too high. Their growing capacities, and sometimes their shifting ability due to previous or current experiences of mental illness, mean that the nature of their involvement can change at any time, and be constantly different. This does not mean that youth are unreliable, rather, that the support they need must be both reliable and attuned to their continuously changing needs. To perceive and respond to these changing needs requires a form of therapeutic attunement on the part of adults tasked with engagement.

This championing of a youth-centred orientation is performed differently by persons in leadership roles within the organization. In this local setting, adults in executive administration roles understand the necessary coordinating roles, the process orientation, long-term thinking, and creative approaches involved in the engagement of a YAC. Rose

acknowledged the resources needed in terms of a 0.5 FTE coordinator. She also described other approaches that she has taken to install other positions who hold this youth focus, such as formal hiring of a Family and Caregiver Advisor as part of the personnel of the Hub, as well as the support of two part-time Peer Navigator roles, who also interact with and witness the activities of the YAC. Though the Peer Navigator positions are part of the Hub model and not solely related to the engagement of youth as advisors, Rose sees them as intrinsically connected to the championing of a youth-centred orientation. Though outside the scope of this dissertation, it became clear through my fieldwork and analysis that the Family Caregiver Advisor and Council bring essential perspectives to the organization that support a youth-centred orientation, and merit further description and discussion.

Much like the work of making youth feel comfortable, welcome and capable, the work of championing a youth orientation within the organization is knowledge work. The decision on the part of administrators at the service site to install these perspectives has begun to extend beyond the Youth Hub and into other parts of the organization. Rose explained:

So, we do have some younger staff in our one programs, and fortunately the one program has been able to free them up enough so that they can sometimes help in other programs. So for example, ... the Early-Psychosis program, they sometimes ask, 'Can [this person] help with this one young male, because we're not connecting?' So here is a mid-20s-year-old, and he starts connecting with this other mid-20s-year old who does not have many social ties So we've done that through paid staff, but you can see the difference. The feeling of connectedness ... being part of a peer group is really important to our youth.

Rose explained that, for her, the work of YE involves implementing hiring practices that infuse that youth-centred orientation as far as possible within the organization. In describing the role of Peer Navigator, she underscored how she wanted the persons holding that role now to move to other roles within the organization in the future. She said:

It's always a challenge, creating part-time or full-time positions, because you do want some movement through the positions so you can expose youth to the learning, the opportunity, and then support them to move on to other professional development or

career paths. But to not limit it, because the more people we can introduce to that role, and even to ACCESS, then the more spread there is of the role ... That's absolutely huge. The group is fantastic and they become your biggest champions.

By implementing these hiring practices, Rose is instituting in the organization an explicit commitment to engagement, moving it from activities 'from the side of the desk' of adults in the organization, and into a structural feature of its budgets and planning. At the same time, it is notable that she would intentionally make this a position of high turnover; though the service-site might conventionally benefit from hiring a single candidate for the long term, Rose chooses to propagate a youth-centred orientation through the organization.

Synthesis: The Standpoint Informants and Institutional Capture

This section sought to understand the work of YE by focusing on the experiences of the standpoint informants, and by tracing up to include the concerns of the National Youth Advisory Council coordinator. While reflecting on the experience of their work in YE, these informants described moments of collaboration and meaningful connection with the YAC members. They relayed their preoccupation with sustaining the right number of youth engaged in the councils. As well, they conveyed their efforts to realize the values of YE, even when sometimes in tension with organizational expectations or realities — such as timelines, job descriptions, and questions of sustainability.

The informants' experiences brought to light what Smith (1987) refers to as “two incongruent modes of knowing,” (p. 82). In reflecting with these informants on their everyday doings — and in particular, on why they do what they do — the values of flexibility, collaboration and reflexivity came up as the principal sources of clarity and guidance in their work with youth. In some instances, working to these values stood in tension with the expectations of their role under a traditional organizational lens. For example, in their efforts to be flexible and attuned to youths' growing capacities, the adults found themselves offering minimal updates to management boards, which brought into question their professionalism. Similarly, though the organizational and project funder expectations are for increasing and sustained numbers of youth engaged, these informants felt that the quality of the relationships and exchanges among the YAC and the organization was more important. These service providers saw this unease in their work: on the one hand,

knowing what they must do to deliver on the values and vision of YE, and on the other hand, knowing the expectations placed on them as professionals within an organization. Their work unfolded in the everyday while holding a dual consciousness of these modes of knowing.

This incongruence is also what Rankin describes as the standpoint informants' knowledge of their work both 'ideologically' versus 'materially' (2017, p. 2). The ideological, in this case, refers to the mandates, theories and explanations that circle discursively around YE, and that these informants and their employers have used to name and explain their roles. The 'material' are the living circumstances of bringing youth to the organization's spaces and processes — it is what these informants *know*, from doing their work. The ideological side of these informants' work signaled the need to examine YE practice texts that have informed them individually and collectively through the ACCESS OM project. These texts will be described and analyzed as a complex of ruling relations in Chapter 5.

At the same time, organizational realities signaled other ruling relations that coordinated the everyday activities of the YAC. The informants displayed a constant awareness of these ruling relations — their material knowledge of their work — and showed adeptness at negotiating challenges.

In reflecting upon this level of data, I continued to follow the thread of the youths' potential of professionalization as a result of a prolonged period of engagement. The time spent waiting while the lease agreement was finalized emerged clearly as an example of trans-local organization of the local experience of engagement. What the youth did during this waiting time became core components of their local character: the YAC members learned to articulate and mobilize their culture through the period of waiting, and in making themselves highly visible harnessed the support of community and parent/caregiving groups. What the adults did during this waiting time also shaped the character of this YE in a fundamental way: implicitly and explicitly, they built up the epistemic resources of these youth so that they could understand, navigate and communicate with the organization and the mental health sector. Whether this knowledge work resulted in professionalization of the youth emerged as a concern in their work, and will continue to be explored as part of the problematic in this study.

The adult informants' agency in YE consists in *how* they negotiate the tensions between ideological and material dimensions of their work. They do so differently, according to the scope of their role and influence within the organization. Nonetheless, writ large, if they had facilitated, scaffolded and supported a different menu of roles and activities for the youth during the time they waited for the lease, the quality and impact of YE may have changed accordingly. What these data revealed were diverse ways of building epistemic resources among the YAC members, and of installing youth perspectives (either directly through youth employees or through family/caregiver advisory roles) in various formal and informal processes at the service site. In doing so, the informants enacted values-based behavior towards genuine, collaborative, flexible and reflexive practice — even when it stood in tension with the expectations of their roles. The presence of this tension suggests that change is taking place, and some level of disruption is occurring. In the section that follows, I explore the impacts of this particular way of implementing YE.

Question 3: How Does YE Impact the Development and Delivery of Appropriate Care?

It is difficult to trace the impact of one factor upon a complex system: cultural and systemic change is due to many forces operating at once. In trying to understand the impact of youth engagement upon this service site, I acknowledge the potential influence of several factors upon the organizational culture and the provision of appropriate care. These factors include particular individuals or groups, new leadership and practices roles, the collective will to change that has amassed through this national initiative, and/or changes in mental healthcare generally at this time. As described in Section 2, the two layers of National and Local Youth Advisory councils mutually influence each other. In a similar way, decisions from the ACCESS OM initiative nationally and locally have had mutual and intersecting influences upon how care is delivered at this service site, and some of these decisions have been influenced by the engagement of youth advisors at the national and local levels.

Seen in this light, YE is a small and possibly unmeasurable factor. Two conceptual aids supported my investigation of its impacts. First, I drew upon Jennings et al. (2006), who have theorized about the potential levels of impact of engaging youth, namely the individual, community and political-change levels, as a means of grounding reflection and evaluation. These broad levels of change emerged naturally in the data of this study. Congruent with

thinking in IE, I further conceptualized these levels as an ecology, whereby levels may constitute each other.

Secondly, in seeking specifically to answer how YE has impacted the development and delivery of appropriate care, I drew upon IE's concern with knowledge politics and the social construction of terms and relations. I looked specifically for the social construction of what appropriate care means, and sought to identify traces of youths' experiences in that construction. In doing so, this perceived change on the nature of care can be linked to the transmission of youths' knowledge within the organization.

In this section, I return to the full sample of informants to describe the ways that youth engagement has impacted the development and delivery of appropriate care at this service site.

Individual impacts for youth: "I love to help others. It makes me feel fulfilled."

The experiences shared by the youth informants consistently showed that youth feel an increased sense of impact, community, meaning and hope as a result of their engagement as YAC members. Sandra said:

I really enjoy it, especially seeing the benefits and the impact of the work we do ... I've made a lot of friends that I like to work with, so many nice people who are so passionate about the same things as I am ... I think also that everybody's here for a reason, whether they've known somebody who's gone through tough mental health problems, or they've gone through it themselves. So they are all passionate, and are there for a purpose, that's to help people get through the tough times.

Sandra said she continued her involvement with the YAC because she values that sense of community. When describing impact of youth engagement on himself, Lloyd said:

I think it's made me feel better because I am helping to change something I've struggled through. And I am really doing something about my experience and making a positive difference ... I feel like what I went through is not going to be in vain, because I can help other people with my experience.

Being able to share their experiences through YE helped these youth to feel that their previous challenges had meaning. This was termed by a YAC member as “a silver lining” to years of struggle and addiction. Another youth, Peter, said:

What I went through, I wouldn't want anyone else to go through, ever. I know some people that are going through what I went through, and that's just how our system works. So just being able to share my voice, and trying to nudge things in the right direction I would've never had as much involvement with mental health if I hadn't gone through psychosis. So it has been part of my recovery process. For a whole year I was on medication — I couldn't talk or speak, didn't want to talk or have any joy. I lost my ability to have conversation with people and figure out what I wanted to say. My brain just shut off ... It's just ... if I didn't have that push, I probably wouldn't be helping, and giving my voice. I did a talk, back in June. I had a conference It was about mental health in the workplace. I gave my personal story, and the reception was incredible. People were coming up to me and saying: 'Thank you for sharing your story' ... I didn't understand how much impact it would have until that happened.

Having the opportunity to share his story, through specific events such as the talk described above, and on a regular basis through the YAC meetings and the YAC newsletter, increased Peter's sense of hope and wellbeing. He added: “I would call this genuine engagement ... Having that platform for youth is truly necessary, and I think there should be more.”

The sense of hope comes from being able to see a role for themselves as contributors. This was also experienced by Max, who said:

I hope to bring ideas to the Council. I'd like to share all these ideas that I have in my head. To create and donate stuff and partner with AOM and the health system. You know I have a few friends who I think might enjoy something like this ... to meet open minded people and I'd say: “I think you should come do this because it's a place that's very open to your ideas. It only takes one person to make a change in the world --- let alone a bunch of people in the room, getting excited about their ideas. Whether it's buttons, or T-shirts, or whatever it is. It's good to see that community of minds together, collaborating.” I love to help others. It makes me feel fulfilled.

Finally, for some of these youth, their experiences of engagement in the YAC also highlighted the negative aspects of their previous interactions with mental health services.

Max said:

It's extremely important to have places like this, because you don't feel judged ... I wish there had been places like this, and I had known about a place like this when I was 14, 15, in high school, stressing about every little thing. If I'd had a place like this to come to ... Oh man!

For Max, feeling that his perspective was needed was helping to heal his previous experiences of alienation from the system of care. The language of system transformation — the notion that mental healthcare needs reform, and significant efforts towards youth-friendly services — validated a sense that things had not been working before.

Appropriate care for youth.

When asked about their views on appropriate care, the youth informants had ideas that contrasted with their previous interactions with the health system, and in particular with services reliant on biomedical and pharmaceutical approaches to care. Peter said:

I think there are so many different levels of mental health ... I think we have this band-aid approach in our society. 'Oh you have this, here's some pills to make it better'. But I think pills is one of the last things that should be used. I learned my own way of taking care of it ... I don't think there is one way of treating someone's mental health. The band-aid approach doesn't go after cause.

An important dimension of appropriate care, for Peter, involved his own agency and choice in developing a plan of care that matched his individual preferences. Peter sees that his role as an advisor involves influencing the range of choices that youth have within the system of care. Sandra also stressed this need for youth to have choice when she described what appropriate care would look like in the youth space:

We'd let them take the lead, so if they don't want to talk to anybody right when they come in, there's snacks and drinks on the table ... There's things to do, and youth [can] sit there and take the time they need to do what they need to do ... there's counselors

here if youth need them, and it's all like their own pace and they end up just coming in and sitting quietly for an hour and a half, and then they leave, that could still make them feel better and if that's what they want, that's what they get. Because we don't want to feel pushy. We don't want the clinical setting, where it's sometimes 'You need to do this. You need to do this.' It's there. These are options. You choose what you think would fit you best and if you would like, we will get you set up with someone who can help to assist you or guide you.

For Lloyd, appropriate care was anchored on the idea that youth are experts of their own experience. Youth engagement, for him, creates an ongoing platform for youth to be taken seriously. He said:

Because they are the ones who have lived through their experience. Only they know how they felt. Other people can't tell them how they felt ... It's a perfect example of what makes good mental health care, in the way that youth are experts of their own stories. So, I have heard from various people that they're not taken seriously, and that they've had people put words in their mouths. I personally have not had that happen to me, but other people have. So, in my experience, I've been taken quite seriously, and a very crucial part of that is in the way that I know my own story, and they respect that.

Lloyd's perspective of appropriate care has an epistemic dimension. It relates to changes in the approach to youths' knowledge of their own lives, and the enactment of these changes when service providers interact with youth at every point of contact, and through the therapeutic relationship.

Describing his experiences with care years ago, Max said: "Sometimes my appointments would barely last half an hour, and she'd ask me how I was doing as she was writing a prescription. This was the feeling of being processed." His role as a YAC member helped Max to articulate his views on why things didn't work for him in the past, and what he sees as necessary for appropriate care now. When asked what advice he would give to a service provider about the way they interact with youth, Max said: "To be more open, to look people in the eye. To have conversations that feel less professional and show you care. Be more

human. Like I'm talking to someone I can look up to, and open up to, instead of feeling judged.”

As noted in these accounts, the youth informants had clear ideas of what appropriate care should be, as well as how it compared to experiences they, or their friends, have had in the past. Their role as YAC members has given these youth a platform to reflect on, articulate, and share these ideas.

Individual impacts for service providers: “It’s about working with them and not pushing them.”

The experiences of service providers also revealed that youth engagement has resulted in individual impacts that include an increased sense of meaning in the work that they do, and feeling supported and motivated regarding the youth-centred orientation of their work.

Service providers holding dual roles (engaged with the council as well as in other service activities that included social work, system navigation, brief therapy and clinical coordination/administration) described that their clinical role is enriched in various ways through their engagement with the youth advisors. Youths’ perspectives give service providers a more nuanced understanding, and a clear rationale, for clinical and administrative decisions that are youth-centred. Lynn described the similarities between her interactions with the YAC and her work as a Peer Navigator as a “youth-centred lens.” She described appropriate care as follows:

Coming together, brainstorming on what the best services might be like for them and kind of giving them the options for them, rather than just telling them what I think might work for them ... Involving them in their own service, and their own care is really important.

Other adult informants noted how the presence of the YAC makes the youth-centred orientation of the model of care clear and concrete for them. They feel empowered to practice with this youth-centred orientation, in particular with regards to the pace of care in their everyday work experiences, because they see that the organization is supporting it through formal roles and a dedicated space. Betty said: “Sometimes it takes us two sessions, or five

sessions, depending on what the youth is presenting with. The main goal is to connect with services that they need, that are best suited for them.”

Fran described how she feels empowered to focus on the youth as a Peer Navigator:

Sometimes they don't know what they need, so it's about working with them and not pushing them to figure that out. It kind of has to be their own journey, and we have the ability to do the peer support, to kind of help them through that. I like that we're not rushed. We're not. You know, we do have to move on, and we have to help other people, but we're able to kind of help them to come to the realization of 'Maybe this is what I do need to focus on' or 'I would like to finish my high school credits.' We have the ability to help them figure out school, how can we best support you or link you to a place that best supports you to finish that. Whether it's increasing social activity, or recreational stuff and of course making that connection to the counselor.

Allowing for more time, and more agency on the part of youth, was seen as a way of healing previous negative experiences with healthcare services. Fran added: “A lot of individuals that we're seeing ... they've had past experiences that were not so great with the mental health [system], so they're a little reluctant to add another service provider to the mix.” This observation resonates with the YAC members' experiences that the system had not been welcoming or respectful in the past, which kept them at bay from approaching services.

Appropriate care for the adult informants.

When asked how they felt that youth engagement was impacting the design and delivery of appropriate care, the adult informants grounded their definition of appropriate care on the diverse and individualized needs that the youth engagement process kept front-and-centre for the organization. Fran said:

Appropriate meaning that it would meet the needs of that individual, being specific to their needs and a best fit for them. Not generalizing everyone's needs into one category, but defining what's appropriate for them, at this time. They may not be ready for trauma work right now ... maybe it's starting here, meeting them where they are. [Appropriate means]... to the person, at a given time.

For Lynn, the involvement of the YAC members acts as a reminder that care cannot be designed for youth, but needs to be created with them. Their participation makes possible a third kind of knowledge, which is brought upon the way practitioners approach care. The practice of appropriate care is very much connected to Lynn's day-to-day role as a Peer Navigator:

To get a feel for what are they looking for, what's their family is looking for, if they're with a doctor, what their doctor might be suggesting. Coming together, brainstorming on what the best services might be like for them and kind of giving them the options for them, rather than just telling them what I think might work for them. Involving them in their own service, and their own care is really important.

As described by these informants, the presence of the YAC at the service site is a concrete reminder of the youth-centred values and orientation of their work. As was noted in Section 2, in Rose's statement, the fact that the YAC members and family/caregiver advisors hold an active place in the organization's culture serves to remind everyone that youths' needs come first. Youth engagement, then, reminds the service providers of this orientation, and makes them feel supported by the organization in taking their time, bringing more of their human side, and focusing on the individual needs of each youth with whom they interact. In this way, the presence of the YAC contributes to the delivery of appropriate care at this organization. Some of these changes, such as the service-providers' leeway to take more time with each youth they serve, constitute a shift in how the organization delivers care, and represent a structural change that will be connected to health outcomes as part of the ACCESS OM national project.

Organizational and community impacts: "Gravitating to the space and the youth centred culture."

The visibility of the youth-centred orientation brought about by the presence of the YAC at the service site has also resulted in impacts at the organizational and community level. As has been developed in the previous sections, the space and decor decisions that characterize the Hub have employed the input of the YAC members, as have certain hiring and personnel decisions within the organization. The impacts of YE upon the clinical practice of the organization become organizational impacts when they are instituted in the budget,

professional-performance and hiring practices, and organizational narrative of the service delivery site. Under this model, the willingness — and ability, on the part of clinicians — to spend more time with youth is possible through the organizational (and model-based) decision to create two FTE Peer Navigator Positions, as well as organize the Hub spatially so there is access to social supports onsite.

Within the Hub space, the new model for service delivery brings together wrap-around health and social services for youth, so that service providers who had not worked together before function out of the same space. As has been stated previously, many of the decisions that led to this model predate the entrance of youth engagement in the local context; however, the presence of the YAC members and family/caregiver advisors makes the youth-centred orientation concrete. The change of space (even at the time of the interim space, which is when data for this study was gathered) has resulted in increased communication and collaboration among mental health system actors in the community. Reflecting on the change that this shared space and shared vision has brought about to the community, Rose said: “The shifts in clinical practice noted in the findings regarding the service providers extend to the everyday decision-making of various other providers from organizations now in partnership in the Hub.” Rose described this as a community of interest: “It’s not only youth and not only service providers in the organization, but a community-wide group that gravitate to the space and the youth centred culture.”

In describing what appropriate care meant to her, Fran stressed the role of community to address the needs of youth:

I hope as a community and as community providers, we are more open to seeing that there are different pathways to achieving the same results. There might be five ways to get them there ... which one is appropriate for this time, for this individual?

A community of interest.

An additional community change brought about by the youth-centred orientation at this organization is a more fluid, communicative and collaborative relationship between the professional and lay perspectives that are invested in youth mental health in the community. The shared purpose that the Hub model and YE activities make visible have increased the

support and advocacy of non-MH-system actors, such as schools, the police, and the Rotary Club. Rose described the increased involvement of various members of the community, including a nurse from the local school board:

With [the School Board's Mental Health and Addictions nurse] coming and working on half an afternoon when she's getting caught up and she wants to work with her peers, have a conversation, and it's totally a community of interest. It's a community of interest they've created, and now feel well supported and now they are networking.

Rose noted that others in the community seem to be shifting their approach in connection to the youth-centred thinking that this model generates. She gave the example of a local police officer who has been able to divert youth with mental health issues from entering the Justice system. She said:

And again, here's another person who is really engaged in this model. He brings the youth sometimes who he's picking up off the streets. He escorts them to the front doors of ACCESS, instead of the emergency department. So that's really a shift in culture, where you see some of the behaviour, and being able to start evaluating if it's criminal behaviour or if it's mental health. You know, and making sure that you don't paint one or the other with the same brush. And that, if it's mental health then, you know, he now feels more equipped with bringing someone to ACCESS, whether it's one of our team members, and he feels quite comfortable coming up the stairs and saying: "[Pam], this is Mark," and to initiate that. So, I think some of the early intervention is avoided because they don't know where to take them.

Multiple points of entry.

As this example suggests, the youth-centred orientation of the local service site, and the attention it has received as a result of engagement activities in the community, creates a different perception of how to approach mental health services, and a sense of community ownership in the delivery of appropriate care. Lynn explained that having multiple points of entry means the other actors in the community see themselves as able to contribute to youth wellness. She said:

So we're actually going [to the schools], and not just meeting with school administration, but actually meeting with the teachers, and meeting with the guidance counselors so that they know who we are. Inviting them to come here. So that's really important. And, yes, it is very important to know people face to face. And we do go into the schools to have appointments as well, because that can be easier for accessing services. So I can do first appointments in the schools.

Rose described other points of entry that have become possible due to the community awareness and trust that activities with high youth visibility have established. She said:

And in a community our size, 110 000, it doesn't take long to spread the word. When you have families and parents and, you know ... it's grandparents who are coming in, and family members, and siblings. When you start getting that mix of individuals who are starting to seek services and appreciate what services are out there ... it doesn't take long to become well known as a core service to the community. Specially through guidance counselors now, we are starting to see that.

If sustained, this is a significant shift in the culture of care, not only within the service site but within the community overall. The ownership that other organizations in the community are taking also means increased visibility for, and scrutiny of, the service model. As the community feels more reassured that services are available, there is increased accountability for these services to be sustained with this particular youth-centred culture. Rose explained:

I think the community is starting to feel more reassured that when they do seek help, it is available. I think that, in the past, we have focused so much on disease, and acuity. So, you know, the individuals with serious mental illness, schizophrenia and bipolar. We've just started to talk about early intervention. We've done that through early psychosis early intervention, but we haven't spent any of the time saying: "If we can help our youth with their anxiety disorder now, then it doesn't have to perpetuate into this lifelong disease." So I think they are starting to see some benefits to that. I think that some of the guidance counselors have seen youth return to school with a more solid plan. Individuals are starting to finish their secondary school and then move on

to university. And they're seeing that this really, there is a lot of potential. That it's not a ticket to a bad future, if you have a mental illness, and the critical piece is how do we get involved sooner than later. So, I think part of the culture is really having to continue to deliver that message.

This kind of visibility and community expectation brings to bear a certain pressure upon the organization to ensure the sustainability of the Hub — and benefits the youth in the community in the long-term. Through the course of this study, the service site accessed Ministry of Ontario funding as a Youth Wellness Hubs Ontario model.

Synthesis: Ruling Relations of the Practice Discourse

The experiences shared reveal that adult informants have both given young people certain knowledge resources and opportunities, and been empowered by the youth-centred orientation that ongoing YAC activities make visible. The YAC visibility keeps the values — the *why* of this story of change — front and centre, freeing up service providers in the organization and in the community to act *against the stream* of previous approaches to care.

The informants connected the visibility of a youth-centred orientation, realized by the presence of the youth and family/caregivers councils, with the ability to envision and deliver appropriate care. For them, the notion of 'youths' needs first' meant being able to attune, respond, and make time for each young person's individual needs in the process of care delivery, even if it means taking more time or being more flexible than their roles had involved in the past. This intersection between the visibility of youth and changes in the organizational processes of the service site mark a significant impact of YE.

In describing their experiences, the informants signal how ideological, professional and organizational relations of ruling are a factor in the way they do their work, revealing their sometimes conscious and intentional negotiation with them. The informants reference the scope and priorities of their particular professional roles as counsellors, social workers and site administrators; they also allude to the professional scope of nurses and police officers in the community. The practice discourse of YE, namely how these standpoint informants were being told to engage via the policy and practice grey literature, emerged as an important ruling relation upon their daily work. In the next chapter, I develop how this discourse is

present and influential upon these informants, and analyze texts that represent it, to discover how it supports and hinders the uptake of youths' knowledge in to the mental health system.

Chapter 5

Findings Part 2

When the informants in this study shared their experiences of youth engagement (YE) — the work, the interactions and the impacts they feel occur — their words drew attention to the material realities of their here and now. As described by DeVault (1994), this minute attention to the details of their everyday begins to ‘unsettle’ the ‘workful character’ of their experiences, and to reveal the ruling concepts and relations that shape them. Such dimensions, continues DeVault, are “‘unrecognized even by those who do [the work],” (p. 228). As such, a valuable contribution that an Institutional Ethnography (IE) lens can bring is in illuminating that link between the material reality and the trans-local ruling relations that shape it.

This core premise, that what is done locally is more fully understood when its trans-local relations are revealed, guided the current research. More specifically, I examined the fieldwork data, looking for trans-local relations. That vantage point supported me in tracing up from the findings in Chapter 4, to locate and examine a particular subset of ruling relations that constitute the practice discourse of YE. Approaching them as a new source of data, I analyzed texts referred to by the standpoint informants as practice guides to their work. It is notable that, in identifying what guided their engagement work, the informants mentioned (and shared, via email) documents that were unconnected with the local policy texts of the service site, or with ACCESS Open Minds. Their focus was on youth-engagement specific texts and toolkits that they consulted when looking specifically for guidance on YE.

The texts drawn upon for this analysis are listed in Chapter 3. The aim of this analysis was to show how the everyday practices of the service providers are organized by the practice discourse, and thus reveal “where institutional power is expressed, made sense of, and enacted by participants” (Campbell & Gregor, 2002, p. 6). The first half of this chapter contains the findings from this examination of the practice discourse.

Provided with this new level of data, I was then able to combine findings from the fieldwork and textual analysis to answer the two remaining research questions in this study. These

questions are: 4) What are the barriers and facilitators of knowledge uptake in the process of YE? and, 5) What ruling relations shape the role of youth as knowers in the context of mental health services design? In the second half of this chapter, I provide findings for those questions.

The Practice Discourse of Youth Engagement

The notion of ‘institutional texts’ refers in IE to any text pertaining to the subject under investigation that has a fixed and replicable character (Smith & Turner, 2014). In this case, the institutional texts studied comprise the practice discourse of YE. This discourse may well be as pluralistic and emergent as the theoretical and empirical scholarship of YE described in Chapter 2. In the case of the professional practice of YE, dedicated roles for the coordination of engagement within a service organization is a new phenomenon, and professional regulations for such work, or even job profiles with such a portfolio, do not exist. As a consequence, the work of YE has not been circumscribed to an institutional course of action — such as forms, processes and policies — that can be qualified as “active” (Proding & Turner, 2013). The adult informants do their YE work without forms to be completed or agreed to, or information letters to be signed. They do, however, look for guidance. They draw upon a number of “higher order” texts that have had historical and ongoing influence over how engagement is conceptualized and practiced. Higher order texts are likely not visible in actual settings, but do coordinate and become activated in the actual settings of people’s work (Smith, 2006). Such activation of texts as ruling relations occurs in different places and at different points in time: people activate texts through their actions as they perform their work. Thus, in nuanced and embedded ways, governing narratives about YE that are shared through national and international policies, training resources, engagement toolkits and webinars get taken up by service providers, and shape the function and operationalization of engagement.

Smith posits that higher order texts do not necessarily rule by prescription, but rather establish the “concepts and categories in terms of which what is done can be recognized as an instance or expression of the textually authorized procedure” (Smith, 2006, p. 83). In other words, these texts have the power to define what it means ‘to do’ youth engagement in the local context. My purposes in critically appraising the concepts and assumptions in these

texts were: a) to articulate how the practice discourse of YE has been governing the work locally; and, b) to reveal what role this ruling relation plays in hindering or supporting the uptake of youths' knowledge into the design of care. The latter was in support of Question 4 in the study; that is, what barriers and best practices exist in incorporating youth-generated knowledge into mental-health service practice. Stemming from the findings from interviews and observations, I also analyzed these texts to uncover the degree to which the practice discourse recognizes the actual work, with particular attention to the time, affect, values-based behaviour, energy, and resources that it takes to engage youth as advisors, as opposed to an idealized or simplified notion of what it takes to engage. I employed this second line of analysis in order to expand upon an insight from my initial findings: that is, that an understanding of the depth and nuances of the informants' work is a requirement to recognize the contextual impediments, facilitators, and effects of youth engagement. Through that process, I also sought an answer to Question 5, that is, how trans-local, embedded and nuanced relations shape the role of youth as knowers in the mental healthcare system.

Findings

In its broadest sense, this analysis reveals a practice discourse of engagement that is heterogeneous, in flux, and highly seductive. It is not easy to dismiss the appeal of an inclusive practice that will empower youth and make the world a better place. However, at the time of this analysis, this discourse is not only commanding in its promise, it is also riddled with problematic interpretations and application of terms, vagueness in its purposes and outcomes, and crucial omissions. While some dimensions of YE practice are over-emphasized with the help of emotional and rhetorical language, others lack sufficient detail or logic. In the following section, I will describe these characteristics of the discourse.

Conceptualizing engagement and the problem it solves.

I took up the questions of how YE is conceptualized and the problem it solves in tandem. By examining how YE is conceptualized, then framed as a solution, I was able to move backwards to identify, deconstruct, and then question the implied problem behind these solutions. In the texts examined, YE is conceptualized somewhat differently based on the author-organization and focus of the publication. In my analysis, I identified a common thread across all texts: that engagement is conceptualized as curative.

Positive youth- and community-development texts.

The texts produced by the positive youth- and community-development sector have a broad and more pluralistic understanding of what engagement does. In conceptualizing YE, positive youth- and community-development texts draw on “rights-based and democratic principles” (YET-P, p. 10). The why of YE is very clear: engagement corrects youths’ exclusion from society, a problem of ongoing concern for scholars in this literature. The purpose of YE, in EYCD-I, is “to empower young people to have a voice in decisions that affect them” (EYCD-I, p. 6). The EEYO-N’s survey of 78 programs and organizations that engage youth did not ask for a rationale for YE. However, the adults surveyed indicated that they do the work they do because it is gratifying and inspiring to see “youth become empowered” (EEYO-N, p. 1). As researchers in this area have observed, empowerment, as a values orientation, is rooted in human rights and social justice, and is seen as having intrinsic value (Zimmerman, 2000). However, the ways this term has been interpreted and operationalized merit question (Clark and Krupa, 2002). I will return to the notion of empowerment in the practice discourse at a later point in this chapter.

The challenge of YE’s curative goal lies in its measurement. Whether engagement results in the inclusion of youth in society, or in the organizations representing it, remains vague in the documents reviewed. These texts offer no guidance towards any assessments of inclusion. Instead, any outcomes measurement of YE occurs at the individual level using a strengths-building approach; for example, the EYCD-I, produced by the Center for the Study of Social Policy, states: “Youth-development activities emphasize positive self-identity and outcomes ... The focus is on promoting personal and social assets, not treating or preventing negative outcomes” (EYCD-I, p. 13). Initiatives designed with this goal in mind are evaluated through the youth involved, because positive self-identity outcomes reside within the scope of individual change, and can be measured across a variety of timelines and settings. However, in conceptualizing the problem as one of youths’ exclusion from society, but the solution as the growth of individual personal and social assets in the youth themselves, these texts gloss over the role of the social and organizational contexts in both excluding/disempowering and including/empowering youth. Moreover, when the emphasis on evaluation has been on individual metrics for youth, the suggestion is that youths’ change is what leads to their inclusion — a framing that relieves the organizational/societal context of any responsibility

and can easily be misread as making youth responsible for their role in society. Finally, the idea that engagement and inclusion are of intrinsic value, though powerful rhetorically, can often lead to no one advocating or working towards these goals directly. Though worthy, these goals may be too vague to appear explicitly in organizational missions, or in the scope of practice or professional responsibilities of service providers.

Linking the value of YE to improvements in youth wellbeing is also a fraught approach because such improvements can only be directly measured on a limited number of youth engaged, and have no translation to a population level. As laudable as it is to improve the wellbeing of the youth in an advisory council, investments in engagement may be directed to larger effect on other health-promoting activities.

The net result of this approach is an over-reliance on descriptive, individualized experiences as a way to define, and assess, YE. For example, the EEYO-N presents the descriptions of YE from multiple respondents in multiple organizations. Without coherence or single collective meaning, YE must be understood as a mosaic of experiences:

It's like chaos, because it's unpredictable. It's like raw energy, because they don't have their values present, don't make their decisions based on established norms. They have the freedom to dream, have ideas and are not afraid of them. It's like a river, because it has a start but no end. A hot air balloon, because the sky's the limit. (EEYO-N, 2002, p. 1)

Though these definitions may have emotional appeal — and may well validate the experiences of others were they to do youth engagement — they provide little, if any, operational and conceptual guidance at the collective level. Instead, they suggest how highly contextual YE efforts must be in order to be meaningful to the specific capacities and experiences of a particular place and time.

Mental health services and research texts.

In texts grounded in the mental-health sector (YI-P, YET-P), YE is presented as a solution to the problem of youth disengagement in mental-health services. The overt or implicit message in these texts is that, should more people with lived experience feel meaningfully engaged with a service organization or program, services would improve (YI-P, MHCCTAY-N).

Lived experience, by extension, is valued as a form of evidence. MHCCTAY-N says, “The experiences of youth have relevance for a number of funding ministries including health, education, colleges and universities, justice, child welfare, and social services” (p.12).

The YET-P describes youth repeatedly as assets that “can help enrich the quality and performance of an organization” (p. 10) as well as “enrich” and improve the “quality of programs” (p. 46). The HTPYP-I states “involving young people improves the quality, relevance and success of research” (p. 2). Even more vaguely, YI-P states that “youth involvement contributes to wellbeing” (p. 2). In suggesting that the fundamental aim of YE is quality improvement, engagement is conceptualized as not only curative, but constitutionally instrumental. Though not addressed explicitly in all texts, the role of YE in improving the mental-health system rests on the assumption that the knowledge brought by youth, patients, or persons with lived experience will necessarily result in positive changes. However, it remains unclear how that knowledge is taken up, or how that positive change occurs. Further, the resources examined do not explore the reality that engagement occurs in a complex system with multiple factors that affect the achievement of services improvement. This omission is crucial given the instrumental and outcome-focused orientation of the texts: since the inclusion of youths’ perspectives is not explicitly pursued for its intrinsic value, investments towards YE could well depend on proof of service improvement, a vast and complex outcome over which YE efforts have limited control.

This indeterminate and fraught framing notwithstanding, the mental-health services and research texts position YE as an imperative. This mandate becomes increasingly problematic when interpretations of what YE can do increase without clear grounding in either the context or the actors involved. For example, the MHCCTAY-N, a consensus document built by youth and adults as part of a consultation process, expands the aims of YE into the responsabilization of youth as experts and managers of their own health. It says, “Emerging adults must be engaged as experts in their own health care and in the management of their own well-being” (p. 20). This is problematic because it frames health and wellbeing as something entirely manageable by the individual, and unconnected with the social and structural conditions of living that affect young people in diverse ways. Additionally, it presupposes that every young person is capable of understanding and accessing protective and therapeutic factors in support of their health.

Health services and research texts.

This combination of instrumentalism and vagueness is also present in texts with a broad focus on health (EYCHS-I, SPOR-N). Whether in health programming or health-related research, these texts state broader improvement goals, with the assumption that youth and/or patient engagement will contribute to such processes. For example, HTPYP-I outlines the goal of “improving the quality and meaning of research” (HTPYP-I, p. 2), while SPOR-N states that “patient-oriented research is ultimately aimed at achieving benefits that matter to patients” (p. 5). In both cases, the relationship between engagement and these outcomes remains vague, and almost tautological. For example, SPOR-N says, “Since patients are at the heart of SPOR, they must be involved as much and as meaningfully as possible in order for health research to be more responsive to the needs of Canadians” (SPOR-N, p.4).

As the practice and discourse surrounding YE develop, its rhetorical emptiness and inconsistencies may be addressed. Increasingly, these texts are beginning to reveal some awareness of the organizational context where engagement takes place. As stated in the YET-P, “Youth engagement is more than a claim that you have youth involved and participating in activities. Its full meaning is connected to the whole approach and core values of an organization and is defined by the level of youth interest and involvement in the planning and realization of each activity” (p. 13). Though these statements are written in language that is both normative and idealistic, the call for examination and reflection on the values stance of the organization is worth heeding. The YET-P rationalizes the diversity of its definitions of YE by saying: “Every definition reflects the mission of the organization behind it, and provides evidence-based, adult insight into youth engagement” (p. 13). While the invitation for every context to define YE for itself is, indeed, attractive, it does not follow, *de facto*, that every definition generated is unproblematic or equally aligned with ethical values. The context, this suggests, cannot be ignored and merits active and ongoing examination.

Idealism: “When youth are at the heart, they become part of the solution.”

Across all texts examined, the most salient feature of the YE practice discourse is its idealism. In the background of engagement efforts, as described in Chapter 2, are multiple ethical, epistemological and human-rights reasons to include previously marginalized perspectives in the processes of society. This is a taken-for-granted, or quickly glossed over,

values assumption of practice texts examined, and one that merits continuous re-enforcement as the practice of engagement evolves.

Without a clear statement of this foundational rationale for engagement, the multiple attempts to define YE rest on an ideal notion of what *it should be* or *how it should be experienced*, rather than on why it should be, or what it does. For example, the YET-P defines YE as follows: “Youth engagement is about empowering all youth as valued partners in addressing, and making decisions about, issues that affect them personally and/or that they believe to be important” (p. 2). At the core of this aspiration are the emancipatory goals of participatory research, including an agenda for inclusion of marginalized perspectives and the democratization of knowledge processes (Camarota & Fine, 2008; Cornwall & Jewkes, 1995; Delman, 2012). However, this aspirational conceptualization of YE glosses over the people, context and structures involved in such processes of inclusion and democratization. Instead, by emphasizing that youth should *feel* valued and empowered as a result of engagement, this framing of YE tacitly puts youth in the foreground of the process. It further assumes that the adults have all the power and responsibility to provoke such feelings. In doing so, it divests the structures, institutions and operant discourses from any role in the process.

Another problematic aspect of the aspirational language in the discourse is that, because it strives for ideals, it closes down any possibility of critique. For example, the EYCD-I refers to the diversity of young people — regardless of their background, culture, race, gender, sexual orientation, family income or other characteristics — who have the potential to speak up through engagement activities. It then states, “Everyone has a voice” (p. 38). This kind of idealistic statement is difficult to argue with, and yet provides no rationale or opening for investigation of how such inclusion occurs. As such, the individual and organizational action needed to make such perspectives heard escapes scrutiny.

Lastly, and in fairly nuanced ways, such idealism makes the youth responsible for change even when they are acting within organizations or processes over which they have no control. This type of statement is exemplified by the EYCD-I logic that: “When youth are at the heart, they are able to influence decisions that affect them and in ways that are meaningful to them. In addition to the power to influence decisions, youth are responsible for contributing

to better results. Instead of passive observers, they share genuine responsibility for making changes. When youth are at the heart, they become part of the solution” (p. 38). By resting on a rhetorical abstraction, “at the heart”, youth are implicated as active actors in a black-box process that presumably leads to better results. Exactly what happens ‘at the heart’ of an organization’s thinking, however, must be transparent in order to understand what youth are influencing. This logic results in very different levels of power and influence for youth if they are at the heart of an organization’s fund-raising activities, versus at the heart of its hiring or evaluation committees.

Lastly, at the core of rhetorical claims that youth *can* become part of the solution, is the suggestion that they are not — placing them instead at the heart of the problem. This underlying portrayal of youth reifies existing marginalization of youth from the processes of society, the very core problem that YE was set out to address. It also sets up a logic where, if YE or system improvement efforts do not succeed or cannot be measured, youth continue to be suspect as the cause of the problem.

What Are the Underlying Values and Principles of YE?

This examination of practice texts revealed an over-reliance on the language of values, with many of them undefined or employed in contradictory ways. While the idealism described above creates a fuzzy, incomplete picture, values construed as tools for implementation provide no real compass for meaning or application. Instead, values must rely for their existence on the quality of the relationship between youth and adults, with no mention of the context, or rules, of engagement.

Empowerment.

The concept of empowerment is a core, underlying value and principle in much of the YE practice literature. It is also one of its most problematic dimensions. ‘Empowerment’ seems to be finding a more nuanced, and less prominent role as the discourse evolves. Nonetheless, it is still the single most prevalent term across the texts examined. It appears seven times in the single page of the EEYO (2002), then about every fourth page in EYCD (2007), YET (2007) and EYCHS (2013). Its prevalence seems to be waning over time: it does not appear at all in YIP (2014), HTPYP (2014), and SPOR (2014). However, it should be noted that SPOR-N is not youth-specific; it is, however, a salient text informing the national ACCESS

Open Minds project, in itself an initiative under the Strategy for Patient Oriented Research of the Canadian Institutes of Health Research.

As noted above, empowerment is often included in the definition of engagement (YET-P, 2007). In much the same way as the other aspirational language qualifying YE, the concept of empowerment is embedded explicitly and tacitly in the texts without a coherent definition. For example, in YET-P (2007), ‘empowerment’ refers to “experiences where youth feel valued and have the power to make a difference” (p. 47). This is a fraught suggestion because it connects the effectiveness of engagement to how youth feel and also, naively, to the notion that they would merely require the empowerment granted by YE in order to make a difference. Such logic sets up YE for failure if the scope of youths’ involvement is relegated to fun, decorative or merely promotional tasks. The discourse fails to describe the scope of the difference aimed for, allowing organizations to ‘empower’ youth to decide the colours of their promotional materials while remaining outside of decision-making processes. Lastly, it remains undeveloped how any difference can occur in the absence of attention to the culture, practices and ruling structures that shape the organization.

Empowerment is also a principle of the EYCHS-I (2013), where it is paradoxically associated with both permission and accountability. EYCHS-I says: “Youth engagement is empowering. It gives those involved the permission to drive change and be accountable for that change” (p.3).

The concept of empowerment has long been considered problematic at the interpersonal level, because of its assumption that some individuals — in this case, the adults — are in the position to endow others with power (Freire, 1970/2000; Masterson & Owen, 2006). In the practice discourse, it seems empowerment itself has an instrumental underpinning, since it allows those who empower young people to offload agency, advocacy and accountability upon the youth themselves. This criticism has long been lobbied on the term empowerment in mental health services specifically: Fraher and Limpinnian (1999) state that health professionals use a language of empowerment to stake superiority within their practice, without changing the actual experience for service users. At the same time, there is also research to suggest that service providers have good intentions to empower service users, even though such power may not be theirs to give (Townsend, 1998). The EYCD says, “

Youth engagement empowers young people to have a voice in decisions that affect them” (p. 6) and also, “Youth determine the discussion” (2007, p. 38). YET-P concludes that one of the keys to fostering youth engagement is to “empower youth to become advocates for their own needs” (YET-P 2007, p. 48). While the precise type of power accorded to youth is not clear, the suggestion is that youth, once empowered, become responsible in negotiating their needs.

If taught to engage through this discourse, persons tasked with YE learn that youth must be or are, as a matter of course, empowered through engagement. Empowerment is either something youth “feel” (YET-P, p. 49) or something that adults “do” for or to them (YET-P, MHCCTAY-N, EYCD-I). Like being “valued” or being “meaningfully engaged”, empowerment must come from the institutions and adults in the context, even when such institutions and adults are not named or examined.

In these texts, empowerment is depicted as an entirely uni-directional construct that fails to convey the complexity of empowerment theory (see, for example, Zimmerman, 2000). Empowerment has long been a key concept in disciplines such as critical, liberation, and community psychology, multicultural and feminist counseling, and social work (e.g., Freire, 1970/2000). Within each perspective, empowerment is central to the work of improving human lives. The multiple levels of application for the term encompass individual, collective and structural considerations. These include: a) a sense of personal control which has been linked empirically to greater health and wellbeing (Chandola, Kuper, Singh-Manoux, Bartley, & Marmot, 2004); b) mechanisms theorized to right power imbalances in society through collective action (Freire, 1970/2000; and, c) an appropriate conceptual model for current dominant trends in the interaction between individuals and professional care, as exemplified by strengths-based psychology and social work, and consumer-oriented mental health care (Cattaneo & Chapman, 2010)

A further suggestion in these texts is that empowered youth become assets to an institution. This framing is problematic in its application in YE because it departs from the intrinsic value of empowerment as a human right, rather than a means to an end.

Linking ‘meaningful’ engagement to the exchange of knowledge.

The term ‘meaningful’ appears as the most recurrent value and/or qualifier in relation to engagement efforts, across all three of the disciplinary areas examined (YET-P, MHCCTAY-N, HTPYP_I, SPOR-N, EYCHS-I). It is difficult to determine what the term means in all these contexts. In texts pertaining to positive youth- and community-development, the notion of ‘meaningful engagement’ is connected to instrumental gains that favour the community. For example, EYCD-I (2007) says “When communities involve youth in ways that are meaningful, they tap new energy, knowledge and leadership” (p. 30). The implication is that the youths’ involvement brings something that is useful or important towards positive community change. However, in these texts, youth themselves determine the degree of meaning that YE has for them, which implies that the community’s benefits are not the only metric of meaningfulness in engagement. Similarly, in the EYCD-I, the degree of meaning is determined by both youth and adults, though the precise nature of that determination is left unclear. EYCD-I says, “‘Meaningful’ means that youth are involved in experiences they consider to have purpose; that the organization makes an effort to be inclusive, and that they both find meaning in the activities” (2007, p. 3).

Texts from the mental-health sector show a shift in the application of the term ‘meaningful’ to encompass involvement in activities that have purpose. The MHCCTAY-N (2017) lists “meaningful involvement in care decisions and system design” (p. 18) as one of its operating principles. The HTPYP-I, which also focuses on mental-health systems design and transformation, warns that tokenism can preclude meaningful change. HTPYP-I says, “Avoid tokenism. Don’t develop something and then get young people to provide input when it is too late to make meaningful changes” (2016, p. 1). In this case, both tokenism and the possibility of meaningful engagement are related to the exchange of knowledge between youth and the organization or adult team. This clearer and more focused application of the term is a characteristic of recent texts, and marks a subtle evolution in the understanding of the purposes of engagement, in contrast to the broader and more idealized goals articulated in earlier texts.

The danger of romanticizing youth leadership.

The concept of leadership also appears in the practice discourse in large numbers, with problematic implications. “Youth leadership” and its related terms and adjectives such as “youth-led” and “youth-driven” appears most saliently in the EYCD, EEYO-N, and YET-P. Its appearance serves to trace the influence of positive youth- and community-development practice and theory, where the notion of inviting youth to engage not only as participants, but also as leaders, is a grounding principle. Such thinking had influence upon the earlier mental-health services research texts. The notion of youth-leadership appears in about every third page of the YET-P, but is otherwise absent in the MHSR texts. Patient leadership, referring to adults, is noted as a marker of success in patient engagement in SPOR-N.

As in all the concepts discussed so far, there is some normative vagueness in the positioning of “youth as leaders and adults as allies” in the youth engagement process (YET-P p. 4). This vagueness may be attributed in practice to the need to contextualize activities, but the blank remains to be filled when it comes to *why* it is important to give youth positions of leadership. It is unclear whether youth leadership is a social justice goal, or a mechanism to keep youth engaged and/or growing in capacity. Another area of vagueness is whether youth have options other than leadership roles, if they want to participate but are not equipped with leadership abilities or inclination.

Beyond vagueness, reliance on the concept of youth leadership is problematic because it solidifies certain assumptions about why and how engagement occurs. As with the term, empowerment, the process of giving youth leadership is entirely predicated on the adults tasked with engagement. They give, or withhold, youth leadership. However, whether these individuals have leadership roles themselves is not specified, though it would be logical to assume that you cannot give what you do not have. In cases of adults tasked with engagement who hold low levels of leadership in an organization, the kinds of leadership they can pass onto the youth can easily result in tokenistic or decorative decision-making, rather than true change within an organization or system. Leading decisions on the snacks to be had at a meeting is a far cry from leading, or even contributing to, decisions on the kinds of staff that an organization hires, or the way it evaluates its services. The conflation of such vastly different decisions under the notion of youth leadership easily enables organizations

and individuals to feel they have achieved the purposes of engagement, when they may not have. A related problematic dimension in the use of youth leadership is that, if leadership results in youth having ownership of the services they co-design, the intended outcome of that shared ownership is unclear.

The use of terms relating to youth leadership, much like empowerment, is insidiously problematic even when many of the more recent texts no longer include this language. People are comfortable with the term, so it is easy to over-employ it and thus omit examination of the actual processes and work that need to take place in order to include youth in the decision-making of an organization. Like empowerment, the idea of youth leadership is easily romanticized to suggest that *all* youth are empowered, or become leaders, through processes of engagement. In reality, it may be that only the youth who can participate as advisors, or even only a segment of those youth, who already have very specific social locations, can gain access to leadership.

Values that relate to context: flexibility and authenticity.

Less prevalent, but still present, are some values of YE that do not rely strictly or solely on interpersonal dynamics between youth and adults, and that point more directly to the way individuals and organizations can operate. The value of flexibility, described as one of the broad conditions of organizational support, begins to address the facilitators for engagement within a context. In describing flexibility, YET-P says, “Although there is no magic formula, there is an openness and willingness amongst youth, adults, and youth-serving organizations to make things work” (YET-P, p. 2). The more recent practice texts — HTPYP-I, MHCCTAY-N, and SPOR-N — also describe support and flexibility as guiding principles. For example, SPOR-N focuses on the need for cultural competence, safe environments, training and financial compensation needed to support “patient participants to ensure that they can contribute fully to discussions and decisions” (SPOR-N, p. 7). The SPOR-N’s focus on adult patients still leaves vagueness around financial compensation for youth. Nonetheless, in all these texts, support and flexibility are seen as mechanisms to increase youths’ capacities and facilitate their continuous input. In this sense, these are operationalizable values because their purpose is achievable, and to a degree, measurable. While adults can certainly be tasked with being flexible and supportive, it is also possible for

the organization itself to be evaluated on such terms. Moreover, application of these values supports the work of persons in the organization, rather than obscuring it.

Authenticity seems to be the qualifier of YE that holds the most grounding upon an awareness of context. EYCD-I says, “To support new ways of working together with young people, we must rethink how our organizations operate” (p. 27). They go on to list organizational characteristics that support such change, including leadership, accessibility, flexibility and collaboration.

Across all texts examined, this question of the values and principles underlying YE was especially generative when seen from the lens of institutional ethnography. IE helped me become attuned to the ways that the emphasis on values can render invisible the actions and decisions that constitute engagement. Characterizing YE as ‘meaningful’ or ‘genuine’ has rhetorical impact, and precludes criticism. At the same time, such over-reliance on values risks hiding the workings of context, structure — including structural barriers — and privilege.

How do we conceptualize adults and their potential contribution?

Broadly speaking, almost all texts in the practice discourse conflated the organizational and structural contexts for engagement into the simple word ‘adults’. Aside from negating the influence of historical and current contexts that shape youths’ role in society, this conflation precludes any understanding of the challenges, effort, and impacts of YE.

While examining the practice texts, a very specific portrayal of the adults in engagement began to build. It was impossible to read about genuine engagement, empowerment or youth leadership without concluding that adults were somehow fully responsible for youths’ exclusion. For example, the tendency in the positive youth and community development texts is to put the responsibility for empowerment on the adults in the organization. The EYCD-I says, “Working together in ways that respect and empower young people usually requires a fundamental shift” (p. 25).

Youth leadership is likewise described in relationship to the adults involved. EEYO-N says, “In order for youth engagement to thrive, adults need to adopt a new lens through which to see young persons — embracing the ideology of youth as being assets today, and not just

leaders of tomorrow” (p. 3). The few mentions of failed youth engagement in these texts also rely heavily on the responsibility of adults. The EYCD_I says: “[Tokenism] sends the wrong message: That adults are not sincere, that they give lip service to the idea of empowerment, that adults are not willing to do what it takes to really give young people a voice in the decisions that affect them” (p. 38).

These characterizations of adults contribute to the invisibility of the work in the particular context, and disregards the training and skillsets required to be the kind of adult that does YE work well. This logic suggests that, for YE to be effective, the responsibility rests on the adults involved to change behaviours and attitudes. For example, EYCD-I says, “To include young people as genuine partners, adults must get past some potentially harmful beliefs and myths. The path is one defined by young people themselves” (p. 36). Even when alluding to organizational limitations, such as timelines, the suggestion is that the adults are choosing to adhere to them, instead of prioritizing youth. The EYCD-I includes the following direction:

Take the time to fully engage and involve young people. Sometimes organizations, officials and communities—often working under a funding or administrative deadline—rush to get a project up and running. Going through the steps to engage young people in meaningful ways and to keep them involved can be time-consuming. (p. 41)

In the MHSR texts, which in this case span 2007 to 2014, the agency of adults continues to be both active and negative, and recognizes more concretely some of the pre-existing barriers that adults have posed in the past. YET-P says, “Reluctance to engage youth in decision-making often stems from adults overemphasizing or exaggerating youth’s immaturity or lack of experience. Even well-meaning adults may see youth as having problems that need to be solved, rather than as possessing talents that can contribute to positive outcomes (p. 3). These texts emphasize a binary relationship between youth and adults, with adults essentialized negatively as “authoritarians, out-of-touch with the younger generation” or idealized as “an intermittent advisor” “mentors” or “trusted guides and lifelong learners” (YET-P, p. 21).

Similarly, the idea of partnership implicitly puts responsibility on the adults while glossing over the ways the organization, institution and society at large may hinder or support equitable partnerships. Some texts do this overtly through the use of imperatives, worksheets

and checklists for adults. Other texts do this more covertly, by mandating a number of activities to be undertaken without any reference to who in the organization will play this role, or how such mandates may be supported or fulfilled beyond that specific individual. The conflation of the organization and the adults tasked with YE renders the diversity of experiences and levels of power among adult workers completely invisible. The HTPYP-I, for example, lists “have clear expectations ... be flexible ... value experience ... involve more than one young person ... avoid tokenism ... provide resources ... provide feedback” (p. 2) as among the things that adults must do when engaging youth. While tokenism is described as something that adults do when interacting with the youth they engage, it can also occur in other, and more subtle ways. For an organization to task a single adult to undertake engagement activities can also be a form of tokenism, particularly if that person has no influence on the culture or operations of the organization.

Two notable exceptions to this portrayal of adults merit mention. First, in the HSR texts, there is an acknowledgement of the need for mutual training and support. The EYCHS-I says: “Capacity building and support for both adults and young people will enable an effective partnership and meaningful participation” (p. 5). “The bar needs to be raised to allow jurisdictions to push the boundaries on the potential to build their capacity to engage patients in truly innovative roles and models of patient engagement” (SPOR-N p. 6.) This acknowledgement of the need for mutual support underlines the idea that YE is new to organizations, and that individuals engaged in the process require training. Adults are not portrayed as all-knowing or all-responsible.

Adults as part of a system.

The MHCCTAY-N also conceptualizes adults differently, in that it portrays them as part of the system, and puts the onus of responsibility on the system (its programs and policies) rather than on individuals. This is evident in the description of inaccessible or unengaging programs due to the nature of staffing. “Many youth and emerging adults can face difficulty finding service providers and professionals that share their racial, ethnic, religious, cultural and linguistic backgrounds and culturally safe and appropriate support can be hard to find” (p. 14). The point of intervention to create more meaningful and effective services lies in the way systems are designed, rather than on the particular dynamics that adults create with

youth. For example, “While most provinces and territories have already amalgamated mental health and addiction services, collaboration and service integration at the agency level remains challenging, despite evidence that better collaboration among mental health, addiction and primary care providers can improve the delivery of services and support EAs most in need” (p. 15).

It should be noted that, even under the suggestion that mutual training is needed, there is inherent responsibility on the adults (rather than the organization) to make YE succeed. On the one hand, adults are characterized as “trusted guides and lifelong learners, who both teach and learn from youth” (YET-P, p. 21). On the other hand, the presence of so many toolkits and recipes suggests that it is adults’ skills and capacities that are missing. MHCC-TAY-N exemplifies this stance: “Ensuring that professionals and policy makers working with EAs on policy and program design have access to best practices in youth engagement is an important component of genuine collaboration” (p. 20). The omission here is for a call to change the structures and policies that would increase genuine collaboration.

Writ large, the YE practice discourse makes adult professionals responsible for both the success and failure of YE efforts. This responsibility is flagged in two ways. In the first sense, professionals are responsible and assumed to not have the appropriate learning resources to engage meaningfully or authentically. In the second sense, their attitudes and behavior are seen as barriers to engagement, and explained as a resistance to empower, or give leadership to, youth. Considerable attention is given to the personal characteristics of the adults who engage as allies, including their ability to be non-judgmental, outgoing, flexible, compassionate, fun, positive, sensitive to the needs of youth, honest, friendly, etc. (YET-P, p. 22). This is problematic at two levels. The emphasis on personal attributes and character omits attention to the professional skills needed to engage youth. Second, this individual emphasis precludes a discussion of how different levels of formal leadership, or the ability to mobilize change within the organization, or in the structures at large, have distinct impacts on what engagement means to the context. Adults who only have the power to get coffee, can only support engaged youth to get coffee. Similarly, adults who can shape the staffing, funding and space allocation of an organization can bring youth perspectives into that realm of change.

The texts examined are still in early, and largely abstract, stages of describing how youth engagement can unfold in an organizational or institutional context. The result is that, though adults are acknowledged as belonging to a larger system, their scope of power within that system is still not addressed as a determining factor on the quality of engagement. Adults are largely responsabilized for the failure or success of YE, and only some texts begin to mention the context of the organization. For example, YET-P focuses on organizational change by broadly describing the five “concrete steps that can be taken to help organizations initiate and sustain youth engagement: 1) Analyze your current position; 2) Create a youth-friendly environment; 3) Get youth on board; 4) Keep youth interested; and, 5) Evaluate with youth” (p. 5). Even within those recommendations, the onus is on individual adults in the absence of a critical understanding of the context.

How do we conceptualize youth and their potential contribution?

In contrast to the suggestion that adults must change their attitudes and behaviours to ensure that youth engage, the practice discourse often portrays young people as a homogeneous population in terms of their social locations and capacities, with the same potential to participate in any opportunities offered. The resources examined contradict this portrayal over time.

In the positive youth and community-development texts, youth are conceptualized as uniformly ready to contribute. The EYCD-I says, “Young people are key to effective community decision making and positive outcomes for local residents” (p. 5). This framing may be reasonable within a community development context, as opposed to a mental health services one, if the assumption is that the youth engaged are not experiencing mental health challenges. However, given incidence rates of such challenges, and the context of exclusion of youth from participation in social processes, such an “add and stir” mentality is optimistic at best. The assumption that bringing youth to the table will easily result in positive change precludes a deeper understanding of the developmental and social conditions of youth. As well, this assumed readiness of youth contradicts the evaluation focus of engagement, which tends to rely on the skills built and individual change in the youth involved. The EEYO-N states, “Most of the programs or organizations we surveyed focus on the skills learned by involved youth. For example, specific skills related to culture, recreation, education,

life/work or general social skills. Additionally, many programs are specifically targeted towards certain youth populations” (p. 1). This focus is individualizing, because it has outcomes and measures predicated on youths’ growth, and their resulting responsibility ‘to contribute’. Moreover, the indeterminate nature of the skills developed raises the question of whose agenda, and whose values, are propagated.

In propagating the idea that youth are uniformly ready to contribute, these texts assume a rational youth who can self-govern, understand the knowledge context enough to interact with it, know and communicate how they want change to happen. This readiness would be a form of epistemic and structural privilege not always enjoyed by a general “youth” population’ let alone among youth with lived/living experience of mental illness.

Diverse but the same.

Alongside the assumption that youth are all in a state of readiness to engage, the discourse sets up a logic whereby recruiting diverse populations of youth amounts to engaging them. As early as 2002, the EEYO-N, in its survey of organizations engaging young people, noted the following populations: “At-risk (21%), gay/lesbian/bisexual (12%), physically challenged (11%), mentally challenged (11%), youth with mental-health issues (9%), ethnic (11%), no specific youth (25%)” (p. 1). It is not clear in this document whether these are the populations of youth served by the agencies surveyed, or youth engaged in advisory or knowledge-sharing processes. More importantly, in spite of this recognition of the diverse experiences encompassed by young people, the contributions of gender, class and race to the experience of YE and the ability to engage are not distinguished. Similarly, the differential approaches needed on the part of the organization to achieve and sustain engagement with youth from these diverse social locations are not mentioned.

The conceptualization of youth, much like the conceptualization of engagement, is riddled with inconsistencies and contradictions. In contrast to the essentializing approach described, texts can also describe youth in a continuum between idealized, though ephemeral, ‘assets’, and hard-to-reach resources who must be kept interested at all costs. When describing youth, the EEYO-N states “They don't have their values preset. They don't make their decisions based on established norms. They have the freedom to dream, have ideas and are not afraid

of them” (p. 1). At the same time, the EYCD-I says, “Sustainability is planned, not taken for granted. Young people age quickly” (p. 57).

A related suggestion is that youth are consistently inconsistent and fickle, and require fun activities in order to stay focused or interested. This framing creates problematic implications on various levels, reifying exclusionary portrayals of youth by society, and shaping the nature of the interaction with adults and organizations. The EYCD-I says, “When activities are fun, young people want to be involved. They know what makes things fun, and it is not long meetings and speeches. Participation is easy when locations and scheduling are convenient and when needed help is available. Retention efforts are deliberate and ongoing” (p. 57). This emphasis on fun experiences suggests that some level of manipulation may be needed to retain youths’ attention. Some texts propose a strong reliance on youth friendliness, new technologies and popular culture as ‘the hook’ to engage young people (EYCD-I, EEYO-N). Indeed, many of the texts examined across all areas relied heavily on youth friendliness and highly-decorative graphic design, as well as informal tone and concept development. The EEYO-N and YIP-N exemplify this approach and its fraught logic. Since it is not always explicit whether youth have been involved in the production of these texts, but the presumed audience and goal are adults/organizations and their professional development in YE, it stands to reason that the priority would be clarity rather than decoration. Instead, the youth-friendliness sometimes contributes to vagueness, and can seem disingenuous or tokenistic. More importantly, there is an assumption that efforts, be they knowledge translation resources or programs, must be brightly coloured and ‘fun’ in order to be youth friendly. This idea reifies a simplistic portrayal of youth as unable to understand or produce thinking and knowledge that is complex, deep and substantial.

It may not be surprising, given the infantilizing approaches described above, that some youth may be hesitant to engage. However, while the discourse portrays youth as a hard-to-reach resource, it does not clarify or deepen understanding about why engaging youth is challenging. Proposing fun processes as the necessary lure omits consideration of the economic, mental or physical conditions that may keep youth unable to engage with a particular organization, or with other community and societal processes.

Instead, the discourse conceptualizes youth as mistrusting of adults. The EYCD-I cites a 1997-survey to describe that: “Three-quarters of America’s youth believed that adults did not value their ideas and opinions, and over 80 percent of youth believed themselves to be unfairly and negatively stereotyped” (p. 30). This representation of youth serves to frame them, uniformly and across time, as being ‘at odds’ with adults and requiring, therefore, fun, leadership and empowerment at the interpersonal level in order to remedy that tension. Such logic precludes employing a structural lens, on the part of both youth and adults, to understand that forms of discrimination such as adultism are not only interpersonal, but also structural and systemic. In terms of how it shapes the work, the logic of youth versus adults leads to strong directives to keep youth happy, hand over power, and avoid any possible stress between youth and adults through processes of engagement.

This type of oversimplified, binary opposition is also present in the HSR texts, where youths’ ideas continue to be posed as antithetical to adult belief systems, and youth as victims of adultism and/or ephibiphobia, or fear of youth. Though the EYCD-I’s reference to a 1997 survey may be dismissed by current YE practitioners as outdated, the need to “regain trust in adults” (EYCHS-I p. 8) is still present in more recent texts. Such a framing precludes any examination of why and how youth may have lost trust with the institution — be it healthcare, mental healthcare or other.

In Mental Health Services Research texts, the conceptualization of youth may be problematic for different reasons. Youth are idealized as “equal partners and agents of social change” (YET-P, p. 21). How youth can arrive at such positions of equality and agency is unclear. As a result, while this portrayal is a values orientation, or an aspirational vision, its rhetoric is merely decorative if the processes necessary for such social change are not explained or followed through. Instead, at the point of operationalizing engagement with youth, these texts characterize young people as “an intermittent resource” with the underlying suggestion of unreliability. Describing how best to work with youth, the YET-P states:

Including youth in goal setting is extremely important because youth are cause-oriented and need something to work towards. However, discussing concepts and plans that involve too much forward-planning may cause youth to lose interest. Developing action plans jointly can give youth focus and fulfil their need to see

results. Working with youth to create structure and direction will help them develop a sense of ownership, responsibility and vested interest in the partnership — key elements in fostering meaningful experiences. (YET-P, 2007, p. 23)

This characterization of youth as resources for change is a far cry from conceptualizing youth at the core of organizational missions or values orientations (e.g. as the people an organization serves). “Youth as resources” not only assumes that youth are there to consistently contribute, but also that the engagement of a resource must result in a positive and quantifiable outcome. The downside of resources in a new public health management and neoliberal environment is that, in the absence of outcomes, there is no rationale for such investments.

A second area meriting attention in the MHSR texts is the suggestion that youths’ engagement equals their ability to wield more power over their own healthcare. Drawing from a well-founded interest in recognizing youths’ expertise over their own experiences, the MHCCTAY-N extends it to expertise over their own healthcare. It frames YE as an imperative, saying: “Emerging adults must be engaged as experts in their own health care and in the management of their own well-being” (p. 20). This positioning is inherently problematic in that it glosses over histories of youth and patients’ marginalization as decision-makers or knowers over their own healthcare (Lakeman, 2010). Given this history, to place youth as experts of their own healthcare may responsabilize them disproportionately. If knowledge resources have historically been denied, it is not justice to suddenly assume, as this discourse does, that they have always been there.

YE in relation to knowledge processes in the organizational context.

Broadly speaking, the practice discourse lacks attention on the organizational context and its influence on both the processes and the effectiveness of YE efforts. All the resources examined provide minimal, if any, description of the organizations, institutions and communities where engagement is mandated.

The texts from mental health services research note that the organizational context has an effect upon the youths’ ability to participate. YET-P says: “If an organization is looking to include youth on its board or on a committee, it is best to ensure that a number of spots are

designated for youth so that they will not feel overwhelmed by the number of adults present” (p. 28). This statement suggests that youths’ comfort centres on the relative numbers of youth and adults, locating once again the effectiveness of engagement at the level of interpersonal dynamics. However, YET-P also advocates for a degree of self-reflection at the organizational level, suggesting that an organization “take an honest look at how it operates” (p. 30), underscoring that organizational readiness for YE is a process. The idea that organizational commitment is necessary for engagement originates in scholarly discussions of youth-adult partnerships. In particular, the YET-P draws on the work of Zeldin and colleagues (2005):

Because it represents a huge shift in how organizations traditionally operate and do business, youth engagement requires significant organizational buy-in. To demonstrate support is coming from the top and exists throughout all levels of the organization, everyone needs to be on board – including external stakeholders such as board members (Zeldin et al., 2005).” (YET-P, p. 3)

The idealistic and aspirational statements that characterize the definition of YE come up again in the attempts to include an organizational lens on how YE unfolds. For example, the EYCD-I says, “Structures and procedures do not get in the way” (p. 60). In reality, the persons tasked with engagement do not have the power to change structures and procedures when and if they represent an obstacle. Statements like this begin to build a tacit responsabilization of the individual service providers. The EYCD-I couches this abstracted terms, further obscuring the nature of the human effort and structural negotiation needed in YE. It says, “Successful organizations are vehicles for facilitating and supporting youth participation, rather than barriers to change. Rules are limited to ensure protection of individual rights, promote participation, and encourage responsible innovation. Flexibility allows young people to contribute in ways that are relevant, meaningful and convenient to them” (EYCD-I p. 60).

Having said this, an increased acknowledgment that the context can provide barriers and facilitators is also evident in texts focused on patient-engagement more broadly. SPOR-N advocates for “a change in culture” (p. 8) that includes training on engagement at all levels of

an organization, and increases capacity for patient engagement by leveraging the existing work and expertise of other organizations/networks.

Establishing organizational buy-in is also an important step in HTPYP-I, YI-P, and EYCHS-I. Such buy-in is most often glossed over as a matter of resources, either monetary or reputational. The EYCD-I states, “An organizational home can increase visibility within the community, provide a base for implementing results-focused strategies, and give young people an important sense of belonging. An effective organization can also help with fundraising and sustaining efforts over time” (p. 60).

Lastly, the EYCD-I listed the following structural factors that influence the viability of YE: “Resistance of institutions, funders, and youth professionals to rethink their purposes and to restructure the way they work; cultural attitudes and economic structures that limit what people believe youth and adults are capable of and can actually accomplish” (p. 33). This statement points to the long-standing exclusion of youth from society that proponents of positive youth- and community-development seek to remedy.

What is invisible in these resources and policies?

The omissions or silences in each of the examined texts contribute to a particular way of governing engagement at the local level. Though limited to a small number of texts, this analysis underscored that the practice discourse of YE is far from monolithic, and its development is difficult to trace in relation to a single narrative of logic or values. Much like the scholarly literature, YE practice has its origins in diverse undertakings, including community youth development, youth leadership programming, engaged citizenship and mental-health/health services research. The limited coherence of the discourse reveals an unquestioned stance that YE is good, even curative; however, much like the empirical scholarship on youth engagement, the practice discourse fails to provide evidence of YE’s purported outcomes. Additionally, unlike the bodies of scholarship that inform YE at theoretical and empirical levels, discussions of YE practice are not subject to peer review, do not undertake preliminary work aimed at understanding how terms have been defined in the field, or anchor within a disciplinary language. That is not their role.

Instead, YE toolkits and practice manuals spring from the ground, echoing the experiences of service providers, program developers, advocates and, sometimes, youth. These texts are published by a wide variety of organizations, often as ‘outputs’ of their engagement or program activities. While their quality of openness and plurality increases the possibility that other organizations will take them up as guidance, it also undermines clarity.

A final significant omission in the practice discourse is a clear examination of how knowledge processes operate as a result of engagement. The rhetorical emphasis on ‘youth voices,’ ‘youth at the table’, and other such constructions fails to illuminate what happens once youth speak up, if they do. In the more recent resources, the possibility of gained new knowledge is framed as part of the collective process. The SPOR-N says: “Patients, researchers and practitioners work together from the beginning to identify problems and gaps, set priorities for research and work together to produce and implement solutions” (p.7).

Synthesis.

Figure 3 below illustrates the relationship between the work of YE and the discourse as a window into the ruling relations that organize the local experience (Luken & Vaughan, 2014). Consistent with IE’s treatment of the concept of ruling relations, the discourse is, in itself, organized by and organizing the work that takes place (DeVault & McCoy, 2002). Extending the idea of co-constitutive relationships further, this diagram illustrates how the context of mental health services delivery is also organizing and organized by the activities locally. In short, all of these elements are constantly affecting each other, both exerting pressure and supporting the unfolding of activities in a particular way.

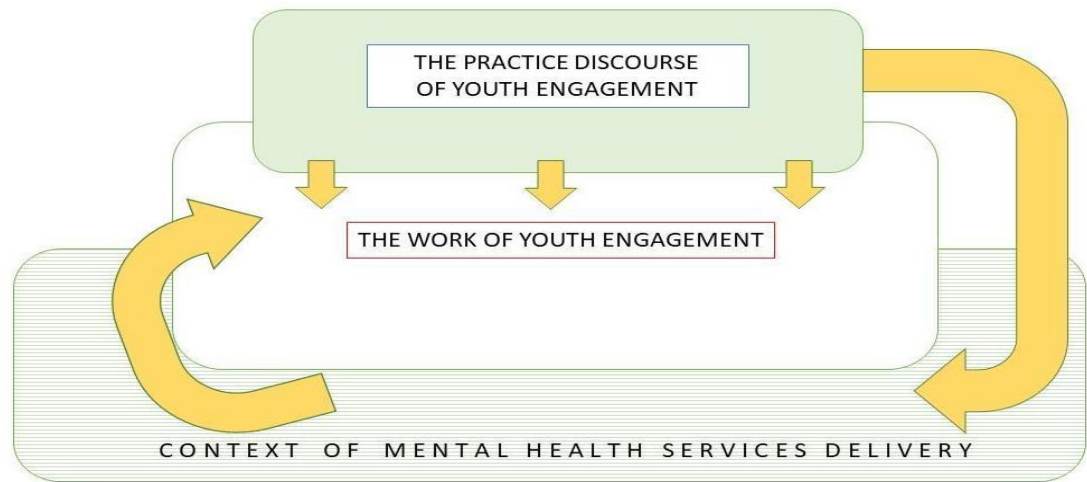


Figure 3: The discourse and practice context for the work of youth engagement.

I present this diagram now to underscore how the discourse is simply one ruling relation exerting influence upon the work, while the work is most prominently shaped by the conditions of its context, namely the service site and the institution of mental health services delivery. I will return to this relationship between context and other ruling relations shaping YE in answering the last question of this study.

While the texts analysed represent only a small sample of the youth engagement ‘training’ materials available, they are enough to show both the promise and risks of its ideology. Analysis of these texts has shown that it contains problematic aspects, vague and indeterminate aspects, and notable absences or omissions that have the potential to shape local practice wherever they are employed. Taken as narratives or experiential accounts of the individual organizations who describe their work in the practice discourse of YE, the contradictions, unrealistic dimensions, and omissions of the texts examined may be understood. However, once put together and promulgated unquestioningly, these texts constitute a complex of ruling relations that can easily constrain and undermine the value of YE in other locations. Together as an ideological construction, they merit caution.



Figure 4: Analysis of the practice discourse of youth engagement.

The practice discourse is far from monolithic, and its constituent parts and language shift according to the organizational, disciplinary and even geographic provenance of the publication. In Fig. 4, I have divided the practice discourse of YE into three broad areas, based on my findings in the analysis. Problematic aspects identified included the vagueness, miss-application and ideological force of the concepts of empowerment and youth leadership, and a troubling emphasis on fun as a crucial feature of YE. Other aspects suffering from indeterminacy, and consequently potential misinterpretation, were the concept of meaningful engagement, the operationalization of an agenda of inclusion and shared power, and the question of outcomes in YE. Finally, areas that the discourse does not develop include the risk of professionalizing youth, the implications of championing within and beyond the organization, and an understanding of the organizational/institutional conditions for YE.

Part 2: Findings for Questions 4 and 5

In this section, I return to the informants’ experiences in order to highlight the linkages and contradictions that exist between the ideology of YE, and its material reality. In considering this combined data, I will provide findings for the secondary questions in this study. These questions were:

- 4) What are barriers and best practices in incorporating youth-generated knowledge into mental-health service practice?

5) How do trans-local, embedded and nuanced relations shape the role of youth as knowers in the mental healthcare system?

Mapping the trans-local and the local.

In order to connect the work of the informants to the discourse of YE, I used the technique of mapping, which is described by Smith (2005) as an integral component of the analytic process of linking people's experiences to the ruling relations that organize such experiences. This process involved examining the accounts and practices shared by the informants, and linking them to what I found in the practice texts. Rankin (2017) describes this analytic step as a type of indexing between the material reality of people's lives and the ruling relations.

Question 4: Barriers and Best Practices in Incorporating Youths' Knowledge

Question 4 in this study sought to illuminate the particular hindrances and best practices in incorporating youth-generated knowledge into mental-health service practice. To answer this question, I engaged with the fieldwork data and the text analyses.

Barriers in incorporating youths' knowledge.

Organizational knowledge culture and pace.

The youth informants said that a barrier to their feeling comfortable, capable of contributing and knowledgeable at meetings was the way content went unexplained or was rushed over by the adults leading the discussion. Lloyd found this problematic in meetings outside of the organization, where he felt "not as valued" and excluded from the proceedings. He said:

It would've been nice if they'd maybe had, one thing that the youth could talk about ... Because I've had things that I could contribute, but the meeting just moves on and I don't get to talk ... I think it might be they're used to moving fast. I also think they don't expect the youth to have anything to say, I think that's the other thing.

Acronyms and professional jargon make participation difficult for youth or other community members not familiar with organizational and professional speak. Sandra, describing her experience with a provincial conference, showed she had internalized a responsibility to understand all this new language when she said, "I didn't contribute anything, or speak at all, but I was able to keep up." Though this was still a positive experience for Sandra, and would

not keep her from engaging in the future, the same cannot be assumed of other youth who might feel excluded by the language and pace of the organizational and services-delivery context.

Similarly, meeting agendas that do not include any items related to youths' knowledge and experience create a barrier to engagement, not only at that particular meeting, but also in the long term. The continued updates on the local lease negotiations are an example of content where youth, and many other community stakeholders, may feel that they have no resources of understanding to contribute.

The pace of public-health management and research agendas.

A particular challenge experienced in this organization was the pace of change in relation to youths' ability and enthusiasm to contribute. While youths' lives changed quickly, and many YAC members moved on to different levels of schooling, different towns, and even full-time jobs, the organization and research processes seemed at times to move very slowly. Though the waiting time was managed successfully enough so that some YAC members maintained their engagement, several of them also moved on. This meant, locally, the loss of various perspectives from youth who had already gained some of trust and comfort with the organization, as well as knowledge of the project. This risk was identified by Rose, who referred to both youth and adult stakeholders when she said:

But I think that probably, still, [a lot of the work] is making sure that we are communicating with everyone routinely enough, making sure that different groups are running ... It's important to keep them engaged and identify how they can continue to contribute. Because once people have had a little bit of a pause, it's easy for them to move on to other areas of interest or commitment.

The informants challenged this conceptualization and also co-opted aspects of the discourse to their ends. On the one hand, instead of reifying the portrayal of youth as inconsistent, or dismissing them as "hard-to-reach", Rose advocated for the investment of a half-time position dedicated to that continuous outreach and communication with youth and parent-caregiver advisors. This investment ensured that, even while the organization or research slows down, youth would remain engaged with the service

site. In turn, this person employs the “youth leadership” and “youth empowerment” impetus of the YE discourse to create and promote activities, using institutional resources, that raise youths’ involvement and visibility in the organization.

Another way that institutional pace hinders the transfer of youths’ knowledge is, conversely, when it moves too fast. As noted by Pam and Maria, tracking change within and as a result of the YAC can be challenging, especially as other activities speed up and demand more time and attention. This is work because it goes against the status quo of organizational pace; at the same time, it is not codifiable as work in the ways that the organization has operated in the past. The reflexive practice and developmental evaluation needed to observe and document change does not yet fit into how the institution ‘measures’ YE.

Previous experiences with unfriendly or inappropriate care.

Previous experiences with unfriendly or inappropriate care set up youths’ expectations that engaging with other providers and service professionals will be unpleasant in the future, and that their views will be invalidated. These experiences had kept some of the YAC members from seeking care, and from considering themselves as potential advisors. In describing his surprise at the welcoming, open tone set in the YAC meetings, Max drew a contrast to his previous encounters with adults in the system when he said, “In the past, I had this one therapist who seemed too professional for me. I couldn’t open up because I felt judged. She was talking more than she was listening.”

Previous negative experiences with the system of care can constitute a barrier to youths’ speaking up at meetings, even once they are engaged as advisors. The practice texts advocated an emphasis on fun and pleasant meetings, as well as dynamic ways of presenting information in ways that is ‘attractive’ to youth (EEYO-N, YIP-N). However, meetings and activities that are solely focused on bright and optimistic thinking may unintentionally deter youth from sharing concerns or experiences that do not align with the positive mood.

While both youth and adult informants referred to instances of youth feeling that the system had excluded them and not listened before, the processes by which this relationship is healed are under-developed in the practice discourse. In processes of YE, a young person who has

felt their knowledge invalidated by service providers in the past may find experiences of being ignored or excluded from the conversation at meetings very distressing, or even re-traumatizing. Some of the texts examined mention the potential disillusionment of youth who engage with the hopes of being listened to by organizations, to meet only with tokenistic approaches. Warnings of tokenism remain abstract in the practice texts, however. In the experiences of engagement shared by informants, what stood out was a general sense of the adults' attunement with youth, a way of interacting together related to the building of therapeutic relationships. Max described this as "looking people in the eye". Even beyond feeling comfortable, youth felt seen.

The discursive youth-adult binary.

The binary between youth and adults is taken up unconsciously by the youth when they describe their engagement as successful because the person coordinating engagement is friendly and welcoming. In doing so, they fail to see the organization or institution whose values she upholds. Though this reliance on the interpersonal experience is a far cry from the characterization of youth versus adults, or of youth as victimized and adults as untrustworthy, it still creates a barrier to the uptake of youths' knowledge because it omits an examination of the context through which such knowledge must move.

It is notable that in this study only some of the informants adopted this youth-adult binary aspect of the discourse, while others did not. Within the YAC, Sandra and Lloyd, the two youngest members, had interpersonal interpretations of the quality of their engagement. Sandra, for example, relied on descriptions of her interpersonal ease with particular members of the adult team when describing her reasons for engaging. She explained that she did not feel intimidated by the adults and therefore experienced a sense of comfort in attending meetings in and outside of the local setting. By contrast, the older youth in the YAC were more disposed to talk about the "setting" — referring to spaces, meetings and conversations — rather than describing the individual attitudes of the service providers with whom they interacted.

This characterization of engagement as dependent on the individual adults, rather than the organizational or institutional attitude, is rife in the practice discourse in ways both overt and covert. For example, some of the resources provided a series of steps, or ingredients, for

adults to fulfill in order generate authentic or genuine engagement (EEYO-N, YI-P). This framing suggests that, if adults were to adhere to these steps, the values accorded to the definition of YE would be met. As such, the underlying problem would appear to be the adults' lack of preparation or know-how, a framing of the problem that begins to construct service providers as independent of the context where they operate, and as the objects of rehabilitation in applying the solution of YE.

Peter, who shared a history of not being listened to by his care provider, connected his YE experiences of participating at meetings, being asked questions, seeing his comments go into notes and follow-up conversations among those attending, as crucial indications that he was being genuinely engaged. Nonetheless, his expectations were tempered because he understood that he was engaging with a system, not with individuals. As he explained, he did not expect everything would change according to his preference, but he did know small changes were possible when he explained what engagement meant to him: "What I went through, I wouldn't want anyone else to go through, ever. I know some people that are going through what I went through, and that's just how our system works. So [engagement] means just being able to share my voice, and trying to nudge things in the right direction."

Bowing to the pressure of over-simplified concepts of youth power and youth voice.

The discursive pressure that youth must have voice and power within a YAC context can quickly become a barrier to the uptake of youths' knowledge. This is another example of how the idealisms of the discourse can constrict the approach to YE, and certainly hinder the uptake of diverse youth perspectives into service transformation thinking and initiatives. The standpoint informants showed concerted efforts that everyone be able to have a voice, when and if they are ready to speak up. This goal was promoted actively and passively in the local practice, through the briefing, waiting, scaffolding, gentle prompting, and then returning to previous discussions so that youth have many opportunities to voice their ideas. Unlike the practice discourse, the service providers did not assume that all youth were uniformly ready to contribute. Instead, they attuned to each youths' capacities and supported them by building their comfort and knowledge so that they could contribute.

However, there is an additional dimension to the focus on 'everyone having a voice' that serves as a barrier to the uptake of youths' knowledge. While the efforts to ensure that youth

at the table feel comfortable enough to engage are laudable, the focused expenditure of resources to build capacity within the group directs energy away from engaging other youth who are most likely to bring diverse perspectives and experiences. A balance is needed between focusing on the YAC members that are already engaged, and dedicating efforts to recruiting other youth, particularly those least heard from.

The double-edged sword of this pressure is that the youth who attend the YAC consistently and over time may become professionalized. While the coordinators seemed alert to this risk, their vigilance was limited to whether the youths' message was changing as they acquired familiarity with the thinking and language of the organization. While they negotiated the nuanced work of not professionalizing existing YAC members, they also paid the opportunity cost of not engaging youth who were absent from their tables.

Best practices in incorporating youths' knowledge.

Not just fun, but welcoming and supportive of youth as knowers.

The practice discourse of YE promotes fun, youth-friendly spaces and adults, and short meetings as facilitators of engagement, with less attention paid to if and how that engagement leads to the uptake of youths' knowledge. The over-reliance on fun merits caution, since consistently pleasant experiences are unlikely to disrupt the established ways that the organization operates, and can tacitly shut down the voices of youth who have different experiences or ideas to contribute.

The local experiences relayed show some use of all these techniques to create fun environments for youth, in an effort to keep them coming back. It was evident that the standpoint informants made efforts to create welcoming and positive spaces and experiences. Fun was evidently had by both youth and adults. However, fun was not a goal in itself; it was a side effect. The majority of the work of the standpoint informants — the things that took effort, affect and purpose — related to making youth feel welcome, comfortable and knowledgeable enough within the discussion so they could speak up. YAC members spoke of the openness of meetings, the flexibility of entry points, the supportive processes that helped them to understand and feel that they had a perspective to contribute. While it may have taken extra time and effort for the adult informants to clarify things to the youth ahead of time, this knowing on the part of the youth made the principal difference on their feeling

meaningfully engaged. Feeling confident in their own knowledge and ability to contribute was more important than fun. Max explained this when he said “I like the meetings are not too formal. I’m not saying they’re not professional ... it’s very casual and very open, open to ideas and open to conversations.”

Active champions within the organization.

The practice discourse has not yet developed an understanding of what roles support engagement within an organization. At this service site, and within the context of the five-year research timeline of ACCESS Open Minds, the half-time YAC coordinator position has brought specific skills in allyship, therapeutic relationships, and relational training to the work of YE. That this work has been dedicated to a formal role has been a crucial contributor in the uptake of youth knowledge into the organization and community. It is worth noting that this individual has social-work/therapeutic competencies, and also performs a half-time role as clinical services coordinator. This particular positioning has allowed the YAC coordinator to transfer knowledge from the YAC to decision-making processes in the organization that affect the culture of care and service provision.

Another important facilitator to the uptake of youths’ knowledge in this context has been the leadership role held by Rose, at the level of site administration. In this role, Rose acted as a conduit and advocate between the mental-health services site and the other divisions of the hospital. She provided an essential link between the national research project of ACCESS Open Minds, thus ensuring that the site’s annual work plan and budget (funded through the national project) enacted a youth-centred orientation through dedicated resources for YE in the form of the dedicated YAC coordinator position. Rose also performed a somewhat similar function between the service site and other community and funder stakeholders, such as the Rotary Club, the school boards, and the Ministry of Ontario. Rose enacted a commitment to YE in her work to create transparency, knowledge resources and opportunities for youth to share their perspectives in meetings and community events where the partners and stakeholders above could listen. Her leadership role allowed for youths’ knowledge to be mobilized to a much larger sphere of influence. Rose’s championship of YE also meant that she took YAC members with her to as many settings as possible, thus increasing their comfort and confidence in speaking up in these settings.

A second crucial element of Rose's championship in this setting has been her ability to formalize roles that infuse youth perspectives into the organization. In supporting and promoting positions held by youth and family/caregiver advisors as part of the structure, Rose created increased opportunities for nuanced, complex knowledge of youths' lived experience to inform processes and care at the service site. She also vested these roles with the flexibility to move at the necessary pace, and the potential to try out diverse activities, in the service of meeting youth at their own level of capacity and respond to the changing (or slowed down) conditions of the lease negotiations and research process. In doing so, she supported the sustained engagement of youth so that the capacities built for their communication with the organization would continue to be applied locally.

In the case of both of these roles, championing at this service site took up the discourse's themes of partnership, empowerment and youth leadership to a degree. The enacted commitment consisted of keeping an active exchange between the YAC members and the organization and community. Pam recognized that it would be easier to follow the way things are usually done, and simply update the YAC members of what other levels of the organization decided to do. She said, "The shift in the council has been about who was leading our engagement activities. For me, to just update the youth [on how the project is going] is hardly engagement at all, even when they provided input and feedback." In both cases, Rose and Pam supported the youth to further develop their own knowledge, and employed strategies whereby this knowledge could be incorporated into the system of care.

Visibility of youth perspectives within the organization and community.

The organization's investment of time and resources have made the YAC members feel that their perspectives are valued. This commitment was made clear by the consistent presence of adults who supported the YAC and its members and in the kinds of events engaging the YAC, service site and the community at large. Even before the Hub space became a permanent reality, and while the space still felt very provisional, YAC members felt that the commitment to youth engagement was genuine. Lynn said: "As a young adult, I've experienced settings in which 'listening' to youth seems to be a formality. I think [this project] is different in that it wholeheartedly trusts that youth know what's best for them." It

is notable that Lynn, who is a Peer Navigator, shares this experience from her perspective as a recent youth, embodying the uptake of youth knowledge into the organizational structure.

The visibility of youth and YAC members in the organization established an important type of accountability between the organization and what they had offered to the YAC members and the community in general. Rose said:

And in a community our size, 110 000, it doesn't take long to spread the word. When you have families and parents and, you know, we're seeing in ACCESS, it's grandparents who are coming and family members, and siblings. When you start getting that mix of individuals who are starting to seek services and appreciate what services are out there, then it's a small community for people to start saying to each other: "Hey if your son is having a hard time, you can, ACCESS is there." And it doesn't take long to become well known as a core service to the community.

Question 5: How Do Ruling Relations Shape the Role of Youth as Knowers?

The data and text analyses show that the following trans-local, embedded and nuanced relations shape the role of youth as knowers in mental healthcare: 1) the culture and practices of mental health service delivery; 2) the culture, goals and design of the national ACCESS OM project; and, 3) the practice discourse of youth engagement.

As described in Figure 5, below, these three elements exert particular coordinating influences upon each other and upon the nature of YE work.

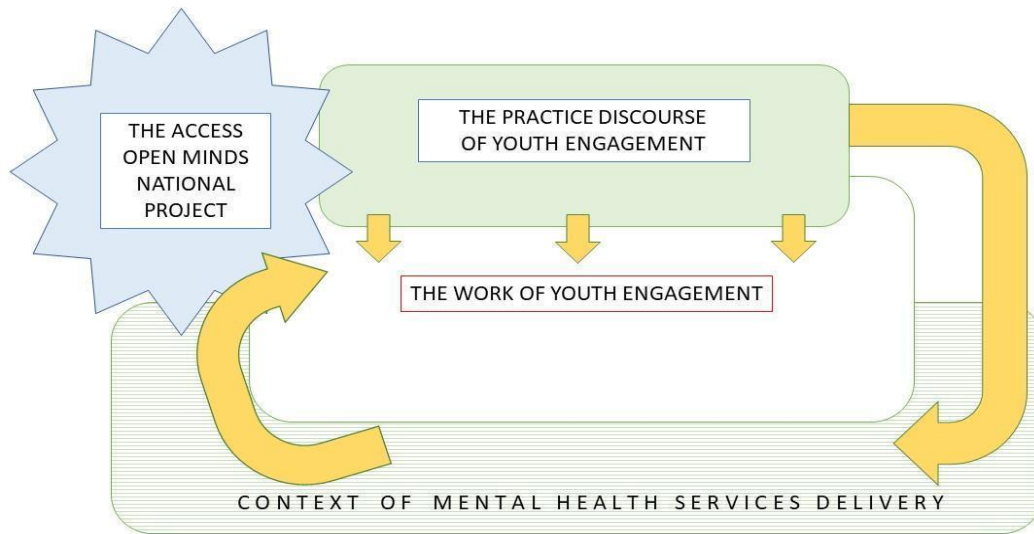


Figure 5: Coordinating influences upon the work of youth engagement.

The culture and practices of mental health services delivery.

The culture and practice of mental health service delivery may be called a ‘context’ within which the activities of this service site occur. This context is a ruling relation in that it exerts a coordinating influence upon the lives of people. Such coordination is seen in the language of both youth and adult informants, and occurs differently based on their diverse social locations and the scope of their professional roles. Rose, who performs a leadership and administration role at the service site, seems to be the informant whose work is most overtly coordinated by the exigencies of service administration. She refers to the realities of the organizational setting as “the business of healthcare”. When describing the organizational commitment to YE, she uses the language of “a .5 FTE”. Questions of staffing, funding and sustainability coordinate her thinking around why and how to involve youth, as well as the ways their engagement needs to be supportive so that they can share their perspectives in ways that are “palatable” to the ears of other stakeholders.

Consistent with Pam’s role as YAC coordinator and Clinical Services Coordinator, she describes YE locally as a process of service improvement, rather than a health promotion process that entails upstream understanding and action on the conditions that promote mental wellbeing among youth. Along with her colleagues, Pam asks the question, “How can we

make services better?” While this positive orientation is important, and the informants and culture of care do not have an illness- or deficits-based orientation, the bounded nature of their operations as service delivery is also notable. As a ruling relation shaping the entrance of youth as knowers in the mental health system, the culture and practice of service delivery precludes consideration of youth who may not want services.

Nonetheless, youth who do not want medical services are still coordinated by this ruling relation. Peter, who views his engagement as a YAC member as part of his recovery, described his efforts to discover his own pathway to health without medication. He still views his experience, even how he interacts as a member of the YAC, in relation to what is understood and expected of the mental health service system. He said:

I try to be reserved in my ideas going forward. I try to be cohesive with the system that I'm working with. Because I do have a very alternative view with what I went through personally. I can't speak to other people's care, what would be best to them, because we all react differently to medication, even how we look at what's happening.

Peter's statement shows that the culture of mental health care exerts definite boundaries on his role as knower. Even though he has been engaged to advise on what would work for other youth, he is careful to circumscribe his expertise only to what works for himself.

The culture and practice of mental health services delivery has a long history both locally and beyond, as well as established ways of working. It is the most powerful and significant form of coordination upon the work of the standpoint informants, and the most salient ruling force appearing in their language. The moments when the standpoint informants privilege youths' knowing over the organizational and service-delivery rules of relation are moments of intentional exertion.

The National ACCESS Open Minds project.

In contrast to the long-standing presence of mental health services delivery as a ruling relation, the National ACCESS Open Minds project is an influence of intense energy and short duration. I have represented it in the diagram as a starburst, to denote its particular energy, enthusiasm and persuasiveness as a ruling relation. The coordinating influence of

ACCESS OM cannot be overstated. The influence of the project upon YAC members was articulated by Sandra when she said:

We all work together, strive for the same things, have the same goals both in ACCESS and out of ACCESS, so that really helps us to be as engaging as we need to be, and to be like as involved as we need to be. I know two people ... in the youth Council who also want to work in healthcare, and are passionate about mental health ... there's a lot of people who want to dedicate as much of their time as they can to volunteering and helping in those areas.

The ACCESS Open Minds project was present and vital in the words and thoughts of all informants interviewed, and the core experience of its coordinating influence is both positive and hopeful. Coordinating effects of this ruling relation upon the standpoint informants included particular tasks and responsibilities, including an evaluation protocol at the service site, and reports to boards and stakeholders. They noted the pressure they felt to translate engagement into numbers of youth. While this pressure may be felt, it did not seem to alter the core approach to build strong relationships with the youth already in the YAC, rather than seeking out larger numbers with weaker bonds. Similarly, the informants noted the pressure felt by the passing time of a research grant while the stalled lease negotiations slowed the perceived progress. Though the informants see the goal of service improvement in the ACCESS OM project, they do not wholesale expect YE to lead to that outcome. Instead, they note that the outcome of service improvement is related to complex factors — and they wisely resist any temptation to claim that YE leads directly to this type of improvement.

Synthesis: The co-constitutive relationship of ruling relations.

The question of whose knowledge counts (Harding, 1991) has been fundamental to the conceptualization of this work. In examining what the standpoint informants do in their every day (Chapter 4), I came to understand the ways the practice discourse — namely prescriptive texts and ideas of what engagement is and which are meant to facilitate their work — influenced the degree to which youths' lived experience can inform the design of care and service delivery.

As a ruling relation rife with intra- and inter-text contradictions and inconsistencies, it is not surprising that these informants take up the practice discourse with a grain of salt. The discourse presents only one matrix of concepts that rule, alongside a larger and older complex of ruling relations inherent in the way mental healthcare is conceived of and delivered, and the way that youth themselves are conceptualized as knowers in society. In the local context, the informants' experiences are also coordinated by the ACCESS Open Minds project, a ruling relation that takes on a youth-centred orientation and values with the objective of improving care.

Seen independently of all these components, the practice discourse offers a heterogeneous mix of regulations and regimes that consistently pose youth and adults in the foreground of the action, and frame the negotiation as one for power and leadership. The discourse increases pressure for this exchange to unfold in paradoxically fun and sustainable ways. In doing so, the discourse impedes the ability to slow down and perceive both the nature of what is happening, and the actual features of the context where it occurs.

There are multiple ways in which an IE lens allows for the emergence of optimism as part of the empirical process of examining ruling relations. The first such way is underlined by the IE observation that ruling relations both constitute and are constituted by the activities at the local level (Smith, 1987; 2003). The work of standpoint informants at this service organization holds the potential to contribute to, and shape, how the discourse develops.

The second area of strength is in IE's ability to take the long view, both in temporal and spatial terms, so that one can see what was too large or all-encompassing to be noticed before. An important contribution that IE lent to my thinking was the consideration of foreground and background as conceptual aids in formulating the relationship between what coordinates and what is coordinated. This practice involves always thinking about the background that the foreground exists upon, and the consequent influence between them. As such, it enables seeing that the discourse is, in itself, the product of a context of much larger scope and standing. Indeed, standing back to take this long-range gaze — the practice and scholarly developments over decades, the rise and growing installation of movements such as Recovery and Early Intervention, and the increased presence of young people behind the podium in diverse settings — we begin to see more clearly the context of epistemic exclusion

in the background of all these constituent parts. There is no better proof that this exclusion has existed than the diverse and visible efforts, in discourse, that now seek to remedy it.

This view enabled me to create the following illustration as a means of explicating the relationship between the larger context where the YE practice discourse occurs and operates as a ruling relation, and the work at the local service site. While all components in this model have the potential to influence each other in different ways across time, the object of my illustration here is to re-instate the importance of this context of exclusion as a coherent and necessary compass in the operationalization of YE in MHSR.

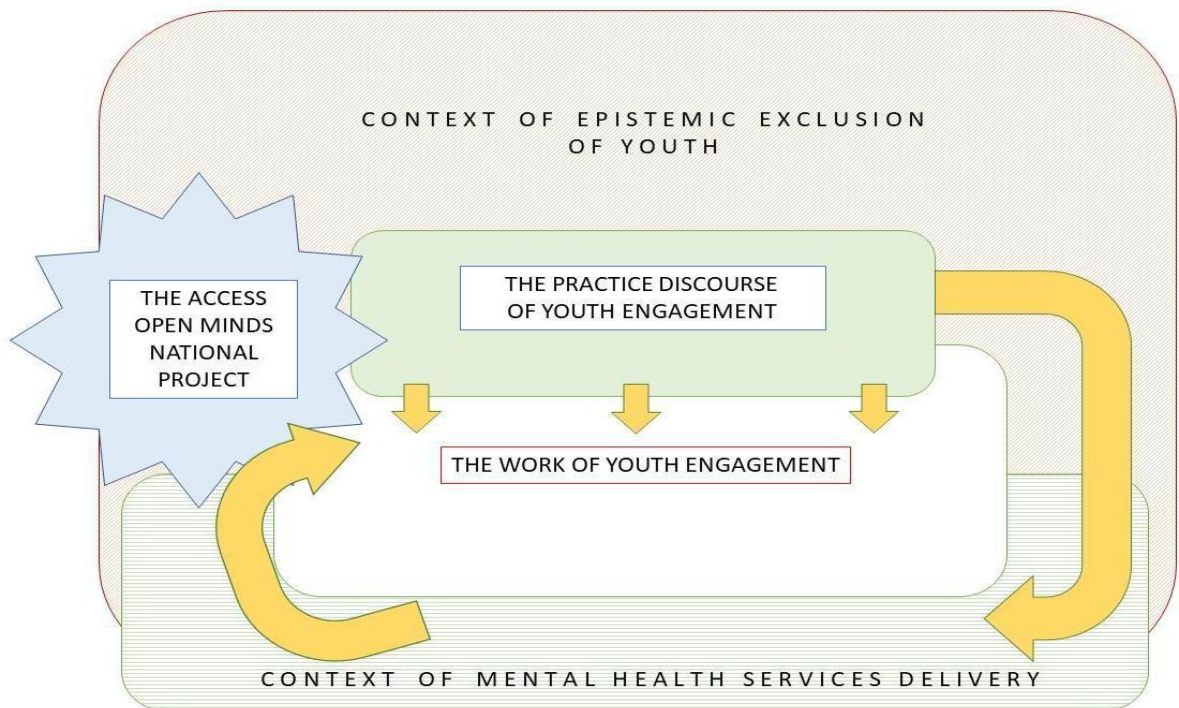


Figure 6: The background of epistemic exclusion and the foreground of youth engagement.

This illustration proposes that engagement is taking place in the foreground, while in the background is a history and context that has been overlooked or under-explained by the practice discourse. This context of historical and ongoing exclusion of youth (and other

populations, including patients) as knowers in the creation of health services has been identified in the development of mental health services research (Fierlbeck, 2011; Lakeman, 2010) and in formative elements of the scholarly treatment of engagement (see for example, Fox, 2013; Freire, 2000; Ginwright & James, 2002). The scholarly understanding of youth engagement has had more opportunity to document and develop an understanding of this context, and has done so with a degree of pluralism relative to the aims and concepts of positive-youth and community development, patient and citizen engagement, and Y-PAR. Acknowledging this context as one of epistemic exclusion aligns broadly with the three bodies of literature, and provides focus to discuss the activities of engagement that the discourse proposes.

In the chapter that follows, I develop the Discussion by describing the relationship between all the findings, the extant engagement literature, and other bodies of literature relevant to this study.

Chapter 6

Chapter 6: Discussion

Youth engagement at this service site unfolds as a constant negotiation between the ideology of YE and the everyday realities of the organization. My analysis of the practice texts revealed a discourse that idealizes YE and individualizes its responsibility onto adult service providers by omitting the nature of the work and ignoring the role of context and structure. This study found that the work of the standpoint informants is situated, pluralistic and complex: YE work responds to the exigencies of the service context at the same time as it seeks to change it. In holding YE both as a core principle and objective of their practice, the standpoint informants resist and revise the YE discourse to support youth in understanding and expressing their experiences.

This dissertation responds to calls for detailed analyses of youth engagement (YE) processes that link the values and aspirations of YE with the realities of implementation. The problematic of this study centred on a persistent concern that the uptake of youths' knowledge — and with it the transformational potential of their contributions — may be diluted and even undermined by the current ideology of YE. This concern informed my efforts to describe the work of YE, as well as its practice discourse, including its problematic, inconsistent, and promising areas.

In this chapter, I will combine these two levels of inquiry and discuss them in relation to the scholarly literatures informing this project. I propose that YE occurs as a situated, pluralistic and complex negotiation on the part of service providers who champion youths' knowledge in the service delivery context. I will then extend this thinking to describe how engagement influences the development and delivery of appropriate care through an enactment of epistemic justice (Fricker, 2007) that supports the uptake of youths' knowledge. A discussion of limitations, implications and areas of future research are included.

Examining the Discourse of Youth Engagement

A high-level question prompted by Chapter 5 concerns how the conceptualizations of engagement developed in the training texts actually play out in the real-life engagement of youth advisors at the local site. In institutional ethnography (IE), it is common to see that

practice texts propose a monolithic, prescriptive view of activities — ranging from the way a child might be brought into protective custody in keeping with social work practices (de Montigny, 2014), to the way hospital admission forms rule the scope of nursing work in practice (Rankin & Campbell, 2009). This, as Smith describes, is the power of trans-local discourses to render work “coordinated into a unified frame at the institutional level” (1999, p. 195).

Although it broadly portrays YE as curative and idealized, the YE discourse was far from unified. The texts examined contained a diversity of experiences, perspectives, and interests, which were reflective of the various contexts and operational realities shaping practice, and of the various methodological and disciplinary values that inform YE. Engagement in the practice discourse is both situated and pluralistic. Finding this level of plurality in the practice texts aligned with other views of engagement in the many disciplines that inform it, and with the calls for increased methods of analysis, theoretical development and evaluation (Foster-Fishman, Law, Lichty & Aoun, 2010).

My analysis identified problematic, indeterminate, and absent aspects of the discourse that require negotiation on the part of the informants. Problematic aspects included a troubling emphasis on fun as a crucial feature of YE, and the concepts of empowerment and youth leadership; these aspects tend to essentialize all youth as a single population, individualize responsibility on the youth for change, and at the same time, dismiss the concerns inherent in their diverse experiences and needs. Indeterminate aspects were the concepts of meaningful engagement and shared power, as well as the question of outcomes in YE; these aspects were fraught because, although indeterminate and potentially misinterpreted, they are normative. Finally, areas that the discourse does not develop include the risk of professionalizing youth, the implications of championing within and beyond the organization, and an understanding of the organizational/institutional conditions for YE.

Youth Engagement as Situated and Pluralistic

In paying minute attention to the daily experiences of YE locally, I was able to confirm that YE looks and is expressed differently by every person experiencing it. The words the informants used to define their experiences with the organization are reflective of the varying individual and collective conditions that attend to YE. In practice, YE will be operationally

diverse because it is situated. The context of engagement — starting from the local table where YE meetings are held and panning upwards to the theatre of mental health services delivery and the institution of healthcare — is rife with social, cultural, political and economic forces that cannot be separated from what YE means or looks like. Another broad finding in this study, supported by the scholarly and practice literature and seen empirically in practice, is that YE is the work of a pluralistic knowledge community who conceive of and apply principles of engagement differently.

The finding that YE is situated and pluralistic is an idea that resonates with the diversity of definitions noted in the practice texts. However, I note also the tension that this represents in the scholarly understanding of YE. Especially in relation to health services research and service-user involvement, the criticism most often lobbied against the practice of engagement is that because engagement is operationalized in diverse ways, it is inconsistent, incoherent and, by extension, lacking in objectivity (Snyder and Engstrom, 2016; Armstrong et al., 2013). Scholars who employ Y-PAR in health and social sciences, community development, and community psychology are more likely to embrace more inclusive ontological and epistemological assumptions in their engagement work; their concerns centre on attention to analysis, documentation and knowledge translation of engagement processes.

This pressure for an ‘objective’ and trans-local approach to engagement may be a remnant of positivist thinking. Institutional ethnography supported understanding how a monolithic ideology of YE can obscure the interactions of context and structure. Webster (2009), in her IE of the social organization of best practice for acute stroke, notes that the literature on evidence-based medicine (EBM) and knowledge translation (KT) tends to represent any variations in practice, in stroke care for example, as a problem to be solved. The failure to provide ‘consistent’ care is attributed to the care providers, responsabilizing individuals for not practicing well, and negating the value of their responsiveness to the context where they operate.

Assistance in negotiating this tension in YE may come from critical researchers elsewhere. For example, scholars in other areas and disciplines have resisted similar pressures, and advocated for a pluralistic, situated perspective. Examples of such resistance include Wodak and Meyer’s (2015) narrative of the development of discourse analysis, and Kinsella’s (2012)

discussion of occupational science as a pluralistic epistemic community. The argument in both cases is that theory choice, and thus knowledge development in both discourse analysis and occupational science will be determined by individuals who have different perceptions of what is accurate, within scope and fruitful in their particular context. Kinsella proposes that, “since individuals will make different judgements, even in relation to the same criteria, it is the shared judgement of the community that effectively decides the fields’ theoretical direction” (p. 5). As it relates to engagement, pluralism represents an opportunity to demarcate its agenda democratically.

Making the work of engagement visible.

This study found that the discursive constructions of YE coordinated, to an extent, what people expect of and do with engagement. This aligns with Smith (2006), who reminds us that texts establish concepts and categories that coordinate people’s consciousness. The most salient coordinating force of the YE discourse is that, in portraying YE as a solution and youth as assets for the future, it is idealized, seductive, and adverse to critique. The fervour of the YE discourse merits caution because it shuts down discussion of the actual work needed to support youth in knowing and sharing. It also trivializes and circumscribes youths’ motivation for engaging, or dismisses the efforts of adult champions as disingenuous or manipulative, all the while omitting any analysis of organizational and institutional factors.

In discussing the chilly climate for women in academia, Smith (1991) describes the distinct form of knowing and working experienced by female academics who navigate personal, domestic and bodily realities, at the same time as they engage with theoretical, abstract and ideological concerns in their academic lives. What these women know, Smith argues, is a distinct way of being academics while also being mothers, daughters and caregivers of others. This way of being was not yet codifiable by the knowledge structures that made up the institution of academia almost 30 years ago. As a result, the ordering of women’s experiences as the institutionally-recognized ‘academic’ subsumed everything else: what they knew disappeared from view, and was invisible to their male colleagues.

Similarly, YE work may also fall from view when entering the organizational and scholarly discourse. Both Smith (2006) and Townsend (1998) acknowledge that describing the everyday world of work is an ‘arduous’ task. Certainly, engagement seems to need minute

detail to convey its nuances, and this is further challenged in a context where communication and information structures are traditionally biomedical, administrative and quantitative. This concern has been experienced similarly in participatory research and in service-user involvement. Armstrong and colleagues (2013) note that critiques of patient involvement have tended to be abstract, omitting meaningful analysis of the processes and structures implicated. Flicker (2008), commenting on similar challenges in participatory research, noted the difficulty in translating knowledge about all the nuances of partnerships given the truncated descriptions demanded by academic journals. Flicker's observation brings into question how much essential nuances of YE may be subsumed in the process of adapting to academic, organizational and policy discourses. This study answered the scholarly call to more deeply understand and describe YE processes (Foster-Fishman, Law, Lichty & Aoun, 2010; Jacquez, Vaughn and Wagner, 2012).

Approaching YE by looking minutely at what the service providers do revealed five types of work: a) building comfort; b) scaffolding; c) creating transparency; d) listening; and, e) waiting. This work happens inseparably from what matters in the organization, including ebbs and flows in service demand, the pace of hospital and research processes, and changes in the landscape of funding and government support. During the months while the local site waited for the lease arrangements to be finalized, the standpoint informants worked to keep the youth engaged by spending time with them, articulating and sharing perspectives and communication vehicles, and attending community and mental health services sector meetings. While this period may be dismissed as a mere waiting period, this study showed that, while 'waiting', the standpoint informants took intentional steps to support youths' growth in understanding each other and the mental health system. They also supported youth in sharing their views about service delivery amongst themselves and in other settings, and in identifying themselves as contributors of knowledge to the project. In keeping with Nastasi (2012), these participatory processes centred on building resources of understanding individually and collectively.

The forms of work identified through this study do not directly correspond to, or align with, what has been visible in the discourse of YE, or in the organization's conceptualization of professional work by its employees. The work of making youth feel comfortable enough to speak up, supporting them to understand the mental health system, or explaining previous

decision-making in the organization has not been codifiable as work in the organization in the past. This work is also, at times, unrecognizable in terms of a research project's expectations of professional work. This finding about the nature of YE work aligns with and extends the observation by Caraballo, Lozenski, and Morrel (2017) regarding the organic quality of knowledge work with populations most affected by social inequities. At this local site, not only the content of the knowledge exchanged, but also the modes of working together, were complex, organic and fluid.

The work of YE is carried out at the local site with the support of the national ACCESS Open Minds project, which holds youth and family/caregiver engagement as both a principle and an objective. This study found that this framing of YE as both a high-level value and a work-oriented task gave the local service providers legitimacy in their work. This legitimacy supported their work even when their particular activities with youth could not be easily categorized under the conventional ways the organization operates, such as social work, counselling or health service administration.

An intentional capture of the discourse in the service of applying values.

Seen from an IE lens, the negotiation that the standpoint informants undertake is an optimal or intentional institutional capture of the discourse and ideology of engagement (Eastwood, 2006). Smith (2005) suggests that this type of intentional capture lends power and legitimacy to what people do in their local setting.

At the individual level, the standpoint informants summon aspects of the discourse of YE to perform their individual roles. Rather than being limited by what the engagement manuals prescribed, the informants used the discourse of YE to propel their work, aligning with the principles and objectives of ACCESS Open Minds. For example, the standpoint informants harnessed values of collaboration and listening to take more time to be welcoming to youth, and to forge trust and comfort in their relationships with both with YAC members and with the youth they serve.

At the collective, organizational level, the informants have also harnessed the enthusiasm of YE intentionally, leading to increased visibility of youth and their needs within the host hospital, the community and sector stakeholders. This visibility aided the organization in

securing funding from community and provincial stakeholders, which in turn ensured sustainability of the Youth Wellness Hub and its youth-centred orientation.

Intentional capture of the discourse is also evident in changes in service-site operations that link the aspirations of YE with the local priorities. This combination is best exemplified in the hiring of a part-time position to coordinate youth and family/caregiver engagement. The other part-time role for this individual is as clinical services coordinator, which complements the YE orientation with knowledge of the site's service patterns and priorities. As such, this role bridges the values and objectives commitment to including youths' perspectives with an understanding of the realities of service delivery.

Humanizing the adults in youth engagement.

Some of the most persistent and fraught elements of the YE discourse include the idealization of youth as 'part of the solution' and the characterization of adults as manipulative or unwilling to 'give up power'. IE proved useful in understanding the effects of this discursive framing. Scholars in other areas of research have employed IE to reveal and challenge problematic characterizations of individual actors. For example, Mykhalovskiy (2003) described the problematic portrayal of physicians as indifferent under the new demands of the Evidence-Based Medicine (EBM) discourse. Webster (2009) extended this thinking to describe the portrayal of community physicians as barriers to the provision of best practice care. In both cases, the EBM discourse tended to individualize service-providers as the single contextual reason a particular course of action is not followed, thus obscuring the structural and organizational factors that contribute to such inaction. In both cases, the discursive pressure upon what the doctors do succeeds in individualizing what are social and structural processes, and precludes action on important barriers and opportunities.

Similarly, in the discourse of YE, adult actors are generally portrayed as unresponsive, unwilling to share power, and even manipulative. The discourse ascribes any failures of YE to adults' unwillingness to appropriately empower young people, charging them with tokenism without exploring the context or scope of their decision-making. This problematic approach to the adults involved in YE does not occur so simplistically in the scholarly literature. Though some researchers do call attention to adults' decision to involve youth tokenistically or too late in presumably participatory projects (Jacquez, Vaughn, & Wagner,

2012), the general consensus is that more information is needed to understand and share effective practices regarding youth-adult interactions, and in particular the organizational conditions that lead to meaningful engagement (Lincoln, Borg & Delman, 2015).

Though the perception that adults were reluctant to give up power did not come up in the local data, idealized/idealizing portrayals of adults as the sole factor for youths' satisfaction with YE emerged both in the practice texts, and in the testimonies by the YAC members. Specially for the youngest members of the YAC, personal characteristics of the YE coordinator were crucial to their feeling welcome and valued. Although this is a positive appraisal on the part of the YAC members, it remains problematic because it is individualizing, and fails to grasp how much of the YAC Coordinator's ability to engage is propelled or circumscribed by conditions in the organization.

Along with Mykhalovskiy (2003) and Webster (2009), scholars in other disciplines have noted this neoliberal tendency to individualize what are social problems between people and institutions, portraying them as an issue of individual concern and responsibility (see, for example, Griffith & Smith, 2014). The upshot of portraying engagement as an issue of youth versus adults is that it obscures the economic, political and other social factors that shape the exclusion of lay persons as knowers in matters of mental health, illness and care.

Paradoxically, while the discourse responsabilizes adults for the effectiveness or failure of YE, it also renders them abstract and invisible. Adults are portrayed as potential champions or enemies of YE, without description or discussion of their expertise, roles, scope of power, and relationship to the decision-making structures in the organization. While scholars have noted that the decision-making power in participatory projects tends to rest predominantly with program staff as opposed to youth (Nitsch et al., 2012), it does not follow that adults have decision-making power over structural and organizational pressures that may be the largest drivers of decisions. Stoudt, Fox and Fine (2012) writing from a Y-PAR perspective, discussed questions of about the amount of power and privilege that adults hold in the engagement processes. They noted the difference between having passive good intentions, and even deep empathy, versus the ability to challenge power structures that shape the process of research and knowledge exchange, and that marginalize and prevent youth from genuinely participating in the research process.

This study showed that the role and scope of power that each adult informant holds significantly alters when and how they can support engagement and, specifically, promote the uptake of youths' knowledge within the organization. Even within this small study, each service provider 'does' engagement differently: the YAC Coordinator supports the youth advisors by providing regular places and spaces where they can create comfortable experiences and a sense of community; there they brainstorm, articulate and share their perspectives in the form of newsletters, interior design plans, and presentations about mental health. By contrast, service providers with leadership positions in the organization are able to install youth positions in the staff complement, to distribute youth perspectives within the service site. These are two operationally different approaches because they are performed by two individuals with different professional expertise situated differently within the context.

The level of power that service providers hold — their ability to mobilize change within the organization, and marshal resources to realize the changes that youth propose — is a crucial determinant in both how they do engagement, and whether/how youths' knowledge is taken up in the organization. This finding aligns with recommendations by researchers to apply an intersectional lens to understanding the positions from which youth engage (Berman & Jiwani, 2014; Fox, 2013; Stoudt, Fox & Fine, 2012), and extends this recommendation to include an increased understanding of the position of adults doing the work of YE in an organization. In addition, it supports the observation by Campbell and Erbstein (2012) that, in order for community-level change to occur as a result of youth engagement, leaders with broad-based skills and networks must be mobilized.

A compass for values-based behavior in youth engagement.

A key understanding emerging from the data is that, because a values orientation must be applied differently by different people in different contexts, it may be difficult to discern intentional values-based behavior in the service of YE, versus other ways of operating as a professional.

Watching the YAC coordinator browsing Pinterest or making snow-cones with the YAC members might not look like engagement that will shape service delivery. Similarly, the application of values may not be evident when a services administrator described her wish for youth positions to be a 'revolving door' within the organization, rather than long-term

employment that sees less shifts in personnel. The approaches described can raise questions of tokenism and absent professionalism. To interpret their actions merely by the vocabulary of the practice discourse, snow-cones with the YAC members may be categorized as ‘just fun’. The ‘revolving door’ comment could be an instance of an adult not really willing to give up power.

This study demonstrated that YE work, albeit intentional, can go undetected when it blends into the operations of the organization. The work of building comfort and trust involved creating moments when youth could relate to one another and gain confidence in speaking up. A position that acted as a revolving door for youth was a means to install champions of YE in multiple points as staff in the organization. In both cases, these ways of working were in the service of increasing the flow of knowledge from what youth know, and what the service site knows. Broadly speaking, these efforts answered an imperative of inclusion which, I came to understand, was the compass of YE at this local site.

Youth Engagement as a Labour of Inclusion

Comparing what the informants do in relation to the pressures of the discourse and the local setting began to reveal the effort involved in YE. The interviews and observation showed that YE goes ‘against the stream’ because it counters the historical exclusion of youth as knowers. In this section, I will describe further how this work has epistemic dimensions.

The effortful nature of YE work was apparent when standpoint informants slowed down the pace of adult-led meetings and scaffolded opportunities so that youth could join the discussion. In doing so, they went against the fast pace, professional jargon and acronyms that characterize healthcare delivery, and which have been noted to have an exclusionary effect (Carel & Kidd, 2014). The service providers are well versed in navigating both the speed and language of these meetings; these skills are an aspect of their professionalism. Nonetheless, they acted against these expectations in the service of including the YAC members. At the same time, I note that the informants did not hand over the meetings to the youth present, slowing to a degree that agendas were not covered. Instead of bowing under a practice-discourse dictum to make meetings fun and engaging so that young people would be able to participate, they found a middle ground by both briefing the youth in advance of the meeting, and slowing down sufficiently so that they could contribute.

As this example suggests, the standpoint informants sometimes went against the very practices that promote professional success in a health services organization. They did this to increase youths' ability to contribute knowledge. This tension between the service site knowledge processes and the YE value of inclusion aligns with observations by Y-PAR researchers about the culture of academic processes, including practices of promotion and publication (Dentith, Measor, & O'Malley, 2012; Fox, 2013). Commentators in the field of mental health underscore that the increased valuing of efficiency and professionalized expertise in service delivery is informed by new public health management, and has exclusionary consequences (Carel & Kidd, 2014; Fierlbeck, 2011; LeBlanc and Kinsella, 2016).

The work of YE in this context sought to counter the exclusionary effects that result from such valuing. In particular, and as noted before, the role of YAC coordinator was installed to support youth so they can understand and participate in the discussion in meetings. As such, this role constitutes a structural innovation in YE, in support of including youths' knowledge in organizational thinking.

Youth engagement as socio-critical work.

In reflecting on their work as coordinators of engagement, the local and national youth advisory council coordinators felt the tension of their work, and said "our roles are not at ease". This statement suggests that coordinating engagement is a continual enactment of a socio-critical view that understands individual actions in relation to a structural whole and, importantly, sees the pathways for improvement. Leonardo (2004), in a reflection on the processes of critical social theory and engagement in education, observes that criticism functions not so much as a form of rejection or dismissal, but rather as a pre-condition for engagement and, ultimately, the articulation of hope.

Similarly, the workful nature of YE at this organization demonstrates that YE is justice work, namely work against the stream of the status quo in defense of those marginalized (Freire, 1970/1993). It aligns with the commitments outlined by Y-PAR scholars, including commitments to challenge institutional ways of being, support and embrace different ways of knowing, and broadly find a proper reconciliation between structural conditions and human agency (Cameron, Murray, McAdam, & Suleman 2014; Kirshner & Ginwright, 2012).

At the same time, however, YE was framed as a concrete objective of both the national and local constituents of ACCESS Open Minds, with an expectation that engagement activities would occur as part of professional roles (local and national) in the project. This finding engages with Smith's (2016) discussion on the scope of public health work in relation to social justice. Smith interviewed public-health officials, finding that although the concept of social justice is routinely identified as a core value for the field of public health, it is unrecognized in what people actually do in their professional roles because it is not clearly defined and made an objective in job descriptions. In this study, the dual framing of ideals and practice for YE was a crucial and defining step in how engagement occurred locally, and had implications on the ways service providers negotiated their role in supporting the exchange of knowledge between youth and the system of care.

Understanding YE through the Lens of Epistemic Justice

This study found that the work and the tensions negotiated by the service providers consistently have epistemic dimensions relating how youth interface with the culture of the local organization and the institution of healthcare. In understanding the nature of this labour in YE work, it becomes possible to think about engagement as an act of justice in concrete ways. In particular, engagement becomes an act of distributive justice because it pertains the just distribution of resources within society (Smith, 2016). The resources in question are resources of understanding and the power to determine 'truth' that shapes decision-making in healthcare (Medina, 2013; Carel & Kidd, 2014). These include both the hermeneutic resources that a young person employs in understanding mental health/illness, and the power that they have to determine the truth of their experience in relation to how care is developed and delivered.

In this section, I will examine the informants' negotiation between the ideology of YE and its reality in practice as a work of epistemic inclusion. I propose that the terms and conceptual direction provided by epistemic justice (Fricker, 2007) serves to understand and orient processes of engagement, as well as evaluate their effectiveness.

Moving YE beyond fun: welcoming and supporting youth as knowers.

The notion that YE must involve fun activities is the most taken-for-granted assumption in the practice discourse, and one that was not empirically supported in this study. The practice texts over-emphasized youths' interest in fun as a requirement of engagement experiences. In doing so, they characterized youth as an inconsistent, ephemeral resource, and a population that must be amused in order to be engaged. However, youth in this study did not perceive themselves or were not portrayed as fun-seekers. Instead, the emphasis on the characterization of youth was on their passion and potential in sharing their perspectives, and the work of engaging them consisted of building comfortable interactions that made communication fluid. Youth and adult informants noted fun was an outcome, but not an objective of engagement at this local site.

Epistemic justice provides a helpful lens to understand the nature and impact of this claim, and to tease out the difference between “fun” and spaces that facilitate knowledge exchange. The discourse's insistence of fun engagement merits critique because it reifies a negative conceptualization of youth as ‘disaffected’ (Colley, 2003), ‘troubled’ (Akom, Cammarota, & Ginwright, 2008; Fox, 2007), and ‘at risk’ (Kelly, 2001). In a context of system reform where various forms of knowledge vie for primacy, such a characterization of youth is a form of identity prejudice. Fricker (2007) describes identity prejudice as “a widely held disparaging association between a social group and one or more attributes, where this association embodies a generalization that displays some ... resistance to counter-evidence” (p. 35). Such prejudice is a type of testimonial injustice, whereby hearers rely on stereotypes to assess the credibility of their interlocutors and have the privilege of determining youths' capacity and credibility as knowers. To follow Fricker's point, were youth characterized as valuing clarity, truth or long-range vision — such as parents, scientists or health administrators are assumed to value in the context of service improvement — their role as knowers in service reform efforts may be approached differently.

Additionally, relegating what youth want from engagement to ‘fun interactions’ is also a hermeneutical injustice. It frames YE to provide youth with fun at the expense of other interactions — for example those that build shared understanding, meaning, or ability to articulate one's perspectives. ‘Fun’ foreshortens the scope of work needed in engagement to

create the necessary resources of understanding among youth, adults, and the system of care. The YAC coordinator's work with Pinterest to brainstorm and articulate the interior design of the Hub exceeds the intention of having fun. It is an act of epistemic justice because she is employing an online tool to create a shared understanding among the YAC members and the organization, thus carrying youth perspectives into the collective knowledge that served to inform the development of the service Hub.

A second argument against the portrayal of youth as merely fun-seeking lies in its dismissal of other reasons why youth might need positive interactions. The work of the informants showed consistent efforts to make engagement comfortable and welcoming, and some youth expressed how this helped them to overcome intimidation and past negative experiences with the system of care. In a sample of four YAC member informants, three of them invoked their previous experiences with the system, for themselves and/or friends. That people were welcoming at this service site surprised them; furthermore, the consistent positive experiences with adult service providers served to revise their understanding of what health services can offer, making their relationship with the system of care more positive. This finding is consistent with other scholars' views regarding engagement in program-design at the clinic level, where positive experiences increasingly supported young people to have positive perceptions of care (Tobin, Chen & Leathley, 2002).

Furthermore, the need to undo the damage of past negative experiences may be occurring at both interpersonal and institutional levels. Townsend (1998) in discussing the work of occupational therapists in a mental health hospital, describes how they work "to heal damage done to the patient's self-esteem and confidence that is incidental to the mental disorder from which they suffer" (p. 10). That engagement increases an individual sense of capacity, identity and self-esteem has long been discussed by researchers in the areas of positive youth development, community psychology, and youth-participatory processes overall (Cammarota & Fine, 2008; Checkoway, 2011; Johnson, 2019, in press; Minkler & Wallerstein, 2011). The findings in this study showed that the work of the service providers, in creating spaces and opportunities for youth to comfortably share what they knew, repaired and strengthened youths' relationship with the system of care.

The YAC members shared a re-established and growing sense of themselves as knowers in relation to the organization as a result of their engagement. They were also perceived by service providers as knowers. Lakeman (2010) and Lee (2019) observe that it is part of the existing culture of mental and social care to underestimate the credibility of service users, particularly in everyday operations coordinated by professional and healthcare management priorities. In this study, the work of YE acted against this culture by facilitating comfortable, slowed down exchanges between YAC members and various adult informants in the organization. The organizational commitment to hearing youths' concerns was made explicit through the ongoing presence of youth and family/caregiver advisors, as well as the various positions that supported such engagement at the service site. In addition to supporting youth to provide their testimony, this commitment created opportunities for others in the organization and community to access and interpret what youth shared.

Examining empowerment in engagement.

Fricker (2013) observed that a gap in collective interpretive resources places certain populations at a disadvantage when it comes to making sense of their experiences. This study showed that each young person held different interpretive resources to make sense of their experiences with mental healthcare, and of the conditions of their lives that promote or undermine their mental wellbeing. This position aligns with fundamental values in participatory processes. Among them is the need for recognition of youth as a diverse and heterogeneous population with diverse social locations (Berman & Jiwani, 2013). Reflecting on Y-PAR processes, Cahill (2007) draws attention to the role of facilitator in supporting the collective building of knowledge resources. Nastasi (2012) reflected on Y-PAR as social justice pedagogy that connects directly to issues of epistemic justice and decreases hermeneutical injustice because it empowers students, who are non-dominant in the structure, to produce counter-narratives that disrupt the hegemonic ideologies.

The concept of empowerment is a salient element of the discourse that the service providers employ through their daily work. When the YAC coordinator described her approach to chairing YAC meetings, she said "I want to empower the youth to see what their agenda will be" she activated the discourse of YE. This activation is what Smith (2003b) and DeVault and McCoy (2002) characterize as an informant being "institutionally captured". The effect

of such capture is that the informant would be invisibly (to herself and others) coordinated by the discourse into thinking she is doing one thing, e.g. empowering, when the effect of her actions is another.

Interpersonal empowerment.

By not setting the agenda of the meeting, the YAC coordinator is effectively making room for the youth to do so, thus ‘empowering them’ to choose the topics of discussion during their time together. Interpersonally, and for the duration of their interaction, she provides the youth with decision-making power that she gives up. She does this in the service of YE. Other service providers also mentioned empowerment in relation to youth decision-making in their plan of care. The conditions of empowerment that these providers created, much like the YAC coordinator’s, centred on providing youth with the time and space to figure out what they wanted to do.

I stress these examples to underline that the standpoint informants in this study used empowerment at the interpersonal level, activating their own professional backgrounds as social workers and counsellors in their approach to empowerment. This is not surprising. Cattaneo and Chapman (2010), in describing the groundswell of the term and its influence upon social work and education practice, note how the replacement of terms such as "client" and "expert" with "participant" and "collaborator" begat an understanding of the professional's role as one of collaborator and facilitator in the journey of individual care. Adams (2003) similarly describes this type of empowerment as rooted in the paradigmatic shift towards ‘self-help’ and ‘user-led’ practice.

Empowerment, as shown in this instance of YE, can only really occur to the degree that the ‘empowering’ adults hold power themselves. Despite her best intentions, it is not within the YAC coordinator’s power to enable youths’ *seeing* their own agenda as a population. Whether they can discern what matters to them beyond the immediate meeting can be influenced by her support only to the degree that she brings a wide diversity of youth to the table and she supports their resources of understanding. For that, the YAC coordinator needs sustained resourcing by the organization.

As it relates to implications of YE in other contexts, this study found that the degree of impact and reach that youths' input can have depends in large part to the influence and power of the adults they engage with. The mechanisms of action between stated youth preferences and their implementation at the service site confirms this. Within ACCESS Open Minds nationally, the National Youth Council drafted a motion that youth and family/caregivers be involved in hiring decisions at every service site; this motion was ratified by the National executive committee. In consequence, the administrator and YAC coordinator at the service site were able to support youth in their involvement in hiring committees. Similarly, informants providing clinical services spoke of empowering youth to co-design their own care plan. This finding has implications for all engagement efforts: if the role of engaging is limited to those powerless in the organization, engagement will likely lead to minimal or merely decorative change. This has long been a concern of scholars: Brown (1995) warned about the use of empowerment as a slogan that ultimately assigns no power to the individual to effect change beyond a temporary and individual condition. MirafTAB (2004), reflecting on empowerment in the context of community participation and development agendas, laments the depoliticization of the concept. She argues that, too often, the concept of empowerment is employed from a western liberal perspective that overlooks the tendency of those employing 'empowering' methodologies to (re)produce forms of hegemonic control.

Structural dimensions of empowerment.

Much like the work of welcoming and making youth comfortable, the concept of empowerment in YE has structural dimensions. It concerns the relationship between youth and the organization, and, by extension, the system of care. As Townsend (2000) described in relation to mental health patients and their ability to integrate into the community, empowerment is as much a condition of community and institutions as of individuals.

While this study found that service providers could empower youth at the interpersonal level, it also found aspects of mutuality in empowerment. In particular, the standpoint informants noted that the youth-centred orientation of the organization/national project empowered them to do their work more meaningfully. It gave them more time to work with youth, and to let youths' own stories and plans for their care-plans emerge.

This finding engages with the historical dismissal of youths' experiences, and or ill-persons' testimony in general, discussed under the lens of epistemic justice. Carel and Kidd (2014) suggest that patients' testimonies are often dismissed as "irrelevant, confused, too emotional, unhelpful, or time-consuming" (p. 530). The service providers' time is coordinated by the organization, and is a structural feature of care delivery. As such, empowering service providers to have longer interactions with youth clients has a structural dimension that shifts the culture of care by providing youth with epistemic justice. This study showed that appropriate care, that is, care specific to the circumstances of each young person seeking service, can only be possible if that person is understood and engaged as a knower.

Youth leadership is not possible without hermeneutical justice.

The concept of leadership was treated differently at the local site from what the practice discourse suggests: though the discourse assumes youth are ready to contribute, the informants' work measured and intentional steps to establish youths' readiness. They accomplished this by paying attention to what each YAC member could do, and then playing to those strengths.

In propagating the idea that youth are uniformly ready to contribute and even lead, the practice discourse assumes a rational youth who can self-govern, understand the knowledge context enough to interact with it, and also know and communicate the kinds of change needed. This assumed readiness is problematic for several reasons. First, because it is form of epistemic and structural privilege that many youth do not enjoy. Scholars in YE and other areas of literature have expressed concern about the lack of development of youths' critical thinking and assessment skills, the lack of appropriate language to navigate conversations embedded in power dynamics, and the kinds of personal and linguistic resources needed to engage in exchanges where there are power differentials (Leonardo, 2004; Negrón-Gonzales, 2015; Stoudt, Fox and Fine, 2012; Rodriguez & Brown, 2009). Additionally, whether or not youth advisors have lived experience of illness, their ability to participate as leaders in the context of health service delivery is further challenged by the historic dismissal of lay persons' testimonies, and the structural privileging of certain types of knowledge (Carel & Kidd, 2014).

These themes were clearly supported in the present data, in particular in the informants' diverse efforts to foster the YAC members' contextual knowledge and ability to lead in incremental ways. The administrator at the site was careful that youth understood the decision-making context before they would weigh in on decisions and make choices. This nuanced, gradual growth in leadership counters the discursive pressure to 'hand over power' and suggests that the process requires concerted and constant effort. This treatment of youth leadership has implications upon the uptake of youths' knowledge because it defines possible leadership in a situated manner, based on what youth can understand and act upon within the context. This finding is supported by Woodgate, Zurba and Tennent (2018), who argue that meaningful engagement of youth and their families in health research includes a process of building capacity and encouraging leadership skills. As a result of this process, Woodgate and colleagues explain, "youth and their families are able to participate, learn, and contribute to knowledge and building relationships that are designed to innovate and improve healthcare systems" (p. 1).

Youth leadership was clearly linked to understanding and voice, and required that youth have the necessary epistemic resources to participate at the various tables at which they found themselves. These varied from YAC-member-only tables to organizational and community-level discussions, and discussions about mental health services outside of the community. That the YAC members expressed comfort with participating at all these levels is testament to the quality of engagement achieved. It aligns with recommendations put forward by Bennetts and colleagues (2011), who described the disconnect between the level at which consumers participate, and the organizational level at which the decisions are made, arguing that organizational commitment to truly involve consumers implies their presence at various levels within the organization.

This study showed that hermeneutical justice, namely the process of building resources of understanding, can occur in various ways by different actors within an organization. The YAC members collectively and individually built resources to understand the context of mental health service delivery. The standpoint informants supported this by traveling with youth to regular national meetings of the ACCESS Open Minds Project, as well as other conferences and roundtables about system reform. These hermeneutical resources were built

in somewhat tailored ways reflecting the individual capacities and interests of the youth involved. The need for such tailoring has been noted by others undertaking youth-adult collaborations and Y-PAR processes. For example, Heffernan and colleagues (2017) highlighted the need for partnership work with youth that is both flexible and developmentally-informed, so as to include varying degrees of involvement, and allow youth to contribute in ways that fit their availability, interest and skills.

Reflecting on outcomes of YE with an epistemic justice lens.

The service providers in this research who were tasked with YE employed a process orientation in their work, and resisted discursive pressures towards outcomes that could not be achieved by their scope of influence or timeline. As the discourse analysis in this study demonstrated, the possibilities of YE that are constructed in the discourse very often align with broader socio-political forces that individualize responsibility and create a fraught outcomes orientation. The discourse is problematic because adults' professional performance is measured solely on the number of youth who attend meetings consistently, or to vaguely deliver on abstract values that are not reflected in the structure of the organization. Echoing the views of other commentators in engagement broadly, the informants in this study stated the need to re-imagine evaluation of both processes and outcomes in YE. In the area of service-user engagement and citizen involvement, a number of scholars have urged further clarity of evaluation (Snyder & Engstrom, 2016; Beresford & Croft, 2004, 2016).

The individual outcomes in youth at this local site link clearly to other empirical work in YE, both long-standing (Cammarota & Fine, 2008; Minkler & Wallerstein, 2011) and newly emergent (Johnson, 2019, in press;). Additional impacts noted include a sense that youths' relationship to the system of care changed through the course of their engagement; it is not clear whether that would translate to increased engagement in clinical services (should they be needed). Nonetheless, this benefit resonates with other findings in the literature (Woodgate, Zurba, & Tennent, 2018).

Another important level where changes resulting from YE may be observed is the broader community, but also in communities of practice with professionals and adult allies invested in YE. This change supports the development and quality of care in the Integrated-Youth-Services (IYS) model, which itself has been claimed to increase access to vulnerable youth

populations (Hetrick et al., 2017; Malla et al., 2018c; O’Keeffe, O’Reilly, O’Brien, Buckley, & Illback, 2015). Further investigation of the role of YE in developing and supporting this kind of community of practice is merited. Specifically, it would be useful to explore the influence of a YAC in the identification and implementation of best practices in the IYS model, such as the hiring and retention of appropriate, youth-friendly staff (Salt, Parker, Ramage, & Scott, 2017).

In relation to mental health services research, and in particular as it informs the establishment and operation of the Hub model of youth mental health services, this study has shown how YE can play a role in the planning and design of IYS sites and services, and in the promotion of relationships between youth and staff (Salt, Parker, Ramage, & Scott, 2017). My focus has been on knowledge exchange outcomes, bounded by my interest in the epistemological aspects of YE. Even within this boundary, it is possible to see that for youth to feel a stronger sense of identity as knowers increases their capacity to approach stigma, their own treatment plan, and possibly roles in peer support. Epistemic agency and confidence are foundational to their interactions with mental healthcare.

This study supports the need to better understand individual outcomes for youth who are formally engaged in mental health governance (Halsall et al., 2019). As the local YAC members transition into adulthood, it is imperative to understand how they apply their emergent skills and identities as system advisors and knowers, as opposed to ‘youth with lived experience’ as they advance in their careers. While seeking this understanding would exceed the research timelines of most participatory or system-transformation processes, its pursuit would align with recommendations to take the long view, when it comes to both participatory outcomes and the development of young people’s skills (Woodgate et al., 2018).

Self-reflexivity in the work of YE.

In their willingness and commitment to continually reflect upon their work with the YAC members, the standpoint informants in this study, and in particular the local and national YAC coordinators, enacted a commitment to critical reflexivity. This commitment was consistent with the principles of a Y-PAR orientation (Berman & Jiwani, 2014; Caraballo, Lozenski, Lyiscott, & Morell, 2017; Fox, 2013). The need for reflexivity in engagement

processes is under-discussed in the practice texts that guide YE, and in much of the scholarly literature pertaining to patient involvement, consumer participation and citizen engagement.

The standpoint informants at this service site exhibited the skills and willingness to be self-reflexive, and an ongoing appetite to continue talking about the practice of YE through regular phone meetings, even since the completion of my fieldwork. The need to institute self-reflexive practice as an explicit and continuous component of engagement represents a promising area of growth. In particular as it relates to YE, the practice of critical reflexivity by all persons involved in a collaboration would support asking about the conditions under which knowledge claims are accepted and constructed. This type of vigilance would future proof engagement against co-option of youths' voices to validate or promote decisions that primarily originate or serve the organization.

Questions of scope and epistemic justice.

Though it may provide a clearer pathway for implementation, framing engagement as the work of epistemic justice still poses challenges to the organizational context. One such challenge is the perception that social justice may be out of scope for organizations concerned with healthcare delivery. In an exploration of the concept of social justice in the field of public health, Smith (2017) found that many officials understand their role to be broadly connected to questions of justice, but that this term and its attendant actions are absent from the organizational and public health missions that guide role and program decision-making. A similar observation has been made in relation to mental healthcare. In exploring epistemic justice and the dynamics between mental health service users and the professional culture of healthcare, Lakeman (2010) reminds us that clinical and professional cultures hold justice lower than other virtues under their mandate. For example, and particularly in mental health, the principle of beneficence is called upon before the principle of justice. He proposes that service providers may be tacitly accepting that social injustice is inevitable, and that "addressing structural inequalities (poverty, systemic racism, etc.) is often considered beyond the purview of mental health services or nursing practice to address (Lakeman, 2010, p. 151). Similarly, inequitable distribution of knowledge resources, be they resources of understanding or credibility, falls low in the priorities of professionals and organizations tasked with healthcare.

Additional tools in countering objections to engagement that centre on the delivery of health services, as opposed to the delivery of justice, may emerge from the approaches devised to implement health equity values. Indeed, participation and engagement of persons with lived experience, and in particular populations whose views have not previously been included, is an established component of the rights-based approach to health equity (Marmot et al., 2008). Efforts to engage and create knowledge with populations who have experienced marginalization help to address health inequities and increase equitable access to health systems through the creation of evidence that is appropriate and tailored for the needs of such distinct groups (Israel et al., 2010; Israel et al., 2019; Wallerstein & Duran, 2010).

The same arguments apply to questions of equity in mental health. Fierlbeck (2011) and others remind us that knowledge from lived experience disrupts a long-standing knowledge hierarchy that has favoured biomedical and pharmacological approaches to care and served particular interests. With Malla, Joober, and Garcia (2015) I note the need for experiential knowledge, alongside equally authentic social, psychological, biogenetic, environmental and cultural ways of understanding and approaching mental illness and health. If the current crisis of burden and service ineffectiveness tells us anything, the exclusion of youths' perspectives from the design and delivery of care has had consequences relating to life and death, and to all principles of justice. Designing and delivering inappropriate care is as much an issue of beneficence as it is of justice. As long as engagement is considered strictly political work, some health care providers and organizations will continue to feel it exceeds their professional scope or practice or ethical orientation. However, when engagement is inextricably connected to transmission of knowledge necessary to developing appropriate, equitable care, its salience in organizational missions cannot be ignored.

Limitations of this Study

The goal of this study was not to be representative of a population, but rather to understand a process in depth. For that reason, the sampling was purposive and took up a specific position to explore how YE occurs the way it does. I employed only some of what are multiple purposive sampling techniques (Campbell & Gregor, 2002). Namely, I traced between YAC members, service providers and practice texts. Another important sampling trajectory would have taken me up to interview higher-level administrators in the host hospital and within the

ACCESS OM project, including its funders and stakeholders in the system of care. This trajectory was out of scope of the present project. Its merits, however, would be significant in terms of understanding how the local YAC members' perspectives informed the decision-making of the larger hospital organization, and of the national service transformation initiative; this could be pursued as future research, either to extend the scope of the present project, or by those examining YE in other contexts.

A related line of inquiry, needing a similar tracing-up into the managerial and executive levels of the host hospital site, could have explored the coordinating texts and discourses associated with hospital administration and decision-making. The discourse of New Public Health Management was not explored sufficiently in this study but is recognized as a coordinating influence upon the operation of health organizations, including those who undertake YE efforts. Future research is required to understand to what degree youth engagement is or can be co-opted towards this agenda, particularly in relation to de-institutionalization and off-loading of care.

The four YAC members interviewed were those accessible and active in the YAC at the time. Though their genders, social locations and lived experience of mental illness varied, it was within a somewhat limited range. The YAC was fairly homogeneous in these respects, and hence the work undertaken to engage may have been far less complex than in a more diverse group.

This project was limited by its timeline and I was not able to observe the YAC members engage in other phases of the ACCESS OM research process beyond the narrative described in this study. A longer research timeline would have allowed seeing the youth engage, for example in analysis of data and evaluation, or in local decision-making processes relating the Hub space once it was open to the public. Observation and interviews around the time of these events would have provided opportunities to see whether youths' knowledge was being taken up, and whether adult perspectives were influenced by the youths' interpretations.

Future Areas of Research

The danger of co-optation of engagement has been raised by several scholars in this dissertation and by others outside of the field. Given the situated and diverse ways that

engagement unfolds, and the contributions of the concept of epistemic justice to YE, the question of co-optation merits further investigation.

A second area of research that interests me is increasing an understanding of how the work of YE could repair and change service providers' relationship or knowledge of the system of care, including what they perceive to be outcomes of YE.

Lastly, an area of future research suggested by but not developed by this study, is the question of how "youth friendly" care relates to therapeutic attunement at various levels of interaction with youth service-users. This begins to translate the responsibility for listening and understanding youths' needs beyond the individual care provider and onto other organizational/institutional levels.

Conclusion

This research afforded me an opportunity to describe and then integrate two storylines of young engagement — that of its ideology and its practice — to examine what it might mean to achieve the emancipatory goal of including youths' knowledge in the design of mental health services.

The on-the-ground story describes the work of engagement as undertaken by people from multiple disciplines, each of them navigating the realities of the service organization, as they interpret how to apply the values of inclusion and collaboration that guide YE.

The YE discourse, in all its ardour and enthusiasm for engagement, poses multiple dangers. First, it risks hindering and subsuming the kind of work needed to support youth in making sense of, and sharing, their own experiences of mental health and mental illness. Further, the discourse trivializes youths' motivation for engaging, pitting them in a false binary against adults whose efforts are portrayed as disingenuous or manipulative. In doing all of this, the discourse responsabilizes individuals for the potential of engagement to cure all or sets them up to fail at an unachievable goal — all the while omitting analysis of the organizational and institutional factors that shape whether or not youth perspectives inform the development and delivery of care.

This study has shown that the work of YE is achieved through constant negotiation between an ideological discourse to engage, and the realities of a service delivery organization. Seen with an institutional ethnographic lens, this negotiation can be best summed up as an intentional capture of selected components of the ideology of YE. Propelled by aspects of the discourse, service providers at various levels of the organization have been able to orient their work towards youths' needs first, a youth-centred orientation modelled to other actors in the sector and community through the active presence of Youth Advisory and Family/Caregiver Advisory councils, positions dedicated to peer support and system navigation, and a part-time position dedicated to the engagement of youth and family stakeholders as advisors.

Analysing this quality of situatedness, plurality, negotiation and tension in YE practice in light of recent work on epistemic injustice proved fruitful for several reasons. First, it made more precise what can sometimes be a vague concern about whether and how YE makes a difference to youth, the organization and the culture of mental healthcare. Secondly, it provided points of intervention to address the disconnect between YE ideology and its practice. Lastly, it served to discern and underscore the necessity of overtly framing YE as a labour of social justice in support of appropriate care and health equity. It is my hope that future research employing Fricker's (2007) theoretical toolkit of epistemic, hermeneutical and testimonial justice will be used to understand and remedy histories of exclusion of diverse populations as knowers, and lay a clearer pathway between engagement and its emancipatory goals.

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Appendices

Appendix 1: Youth Interview Guide

Interview Guide for Youth

Information about This Research

This research project is designed to learn about your experiences of doing youth stakeholder engagement within the Open Minds Chatham-Kent project. In these interviews, you are asked to describe how you have been involved, and what this has been like for you. You can share as little or as much as you feel comfortable sharing. There is no wrong way of answering these questions. In our conversation, I'm really interested in descriptions of your experience that make sense with your way of speaking and living your life.

Information and Consent Letter Signatures

In order to use the information that you share with us, you will need to read and sign this letter. You can keep it with you for future reference, but I need to take the signed form.

rapport-building

Because the researcher has had prior opportunities to meet the majority of interviewees, rapport-building in this context focuses on re-establishing the acquaintance with the interviewer and on bringing the conversation to the present moment. One question I will ask is: Since we met for the first time at [date], how you had any questions about this research, or for me, that we can discuss today?

Interview Questions

1. Tell me about your work with the Youth Advisory Council. What do you do? And what has it been like for you?
 - a. What kinds of activities do you take part in? What are they like?
 - b. How do these activities get planned?
2. What, in your opinion and experience, is youth engagement about? What makes it work well? What makes it work badly?
3. What are your meetings like?
 - a. How are the agendas for these meetings set? Who decides what will be discussed?
4. Can you think of a moment when you wanted to add something to the conversation at these meetings? What is that like?
 - a. Describe the experience of contributing to the meeting.
 - b. Did you feel you said everything you wanted to say?
 - c. Did you feel satisfied with how your ideas were heard?
5. If you were describing your role in this project to other youth you know, what you would you say to them?

6. When you hear the sentence "youth are experts of their own experience", what does that bring to mind?
7. Where do your ideas come from? What about other youth in the Council?
8. What do you hope will be done with your ideas and knowledge? What sorts of things support this? What gets in the way?
9. Describe an experience when you or another youth in the YAC felt their/your ideas made a difference.
 - a. What kind of idea did you propose?
 - b. Who took it up? What happened?
10. Are there reading materials that you've come across in your work with the Youth Council? Can you recommend anything you've read here that was interesting or useful to you?
11. What do you think make for good, appropriate mental healthcare for youth?
12. Do you have any questions or comments for me?

Appendix 2: Interview Guide for Adults

Appendix 2: Interview Guide for Adult Professionals

Information about This Research

This research project is designed to understand the experiences of doing youth stakeholder engagement within the Open Minds Chatham-Kent project. In these interviews, you are asked to share as little or as much as you feel comfortable with. There is no wrong way of answering these questions. In our conversation, I'm really interested in descriptions of your experience in your own language.

Information and Consent Letter Signatures

In order to use the information that you share with us, you will need to read and sign this letter. You can keep it with you for future reference, but I need to take the signed form.

Rapport-Building

Because the researcher has had prior opportunities to meet the majority of interviewees, rapport-building in this context focuses on re-establishing the acquaintance with the interviewer and on bringing the conversation to the present, embodied moment. Depending on the circumstances, I may talk with youth or adult professionals about the space we are in, the meeting just concluded, or their plans after we complete our interview. One question I will ask is: *Since we met for the first time at [date], have you had any questions about this research, or for me, that we can discuss today?*

Interview Questions

1. What brings you in connection with this project?
 - a. How did you come to being involved?
 - b. Tell me about your work with the Youth Advisory Council. What's it like?
 - c. How do you feel after it's done? What do you do next?
2. What, in your opinion and experience, is youth engagement about?
 - a. What makes it work well?
 - b. What makes it work badly?
3. What are your meetings like?
 - a. How do they feel?
 - b. What surprised you about them?
 - c. Can you think of a moment when youth added something to the conversation at these meetings? What is that like?
4. Do you feel the working group is often able to take up the ideas proposed by youth? What supports this? What gets in the way?
5. If you were describing your role with Youth Advisory Council Youth to a peer professional, what would you say?
 - a. What would you recommend to this person do as they prepare for a similar role?
 - b. What changes in your daily work, daily and weekly schedule are involved in this role?
 - c. How would you say this role changes your everyday practice?
6. When you hear the sentence "youth are experts of their own experience", what comes to mind?

7. What do you hope will be done with the ideas and knowledge youth bring to these meetings with the YAC and working groups?
8. Are there reading materials that you've come across in your work with the Youth Council, or in your practice here with youth? Can you recommend anything you've read here that was interesting or useful to you?
9. What do you think makes for good, appropriate mental healthcare for youth?
10. Do you have any questions or comments for me?

Appendix 3: Characteristics of Interviews Using Institutional Ethnography

Analytic concept	Analytic intent
<i>Inquire from a perspective rooted in the activities of standpoint informants. This position is maintained throughout the inquiry that explicates how organizations work.</i>	<i>Learn about the issues, tensions, and contradictions that people experience in their lives (problematic).</i>
<i>Examine work practices and processes in organizational and bureaucratic settings in such a way that the researcher "think[s] organizationally" (D. SMITH in DeVAULT & McCOY, 2004, p.758).</i>	<i>Orient interviews toward features of social life that link standpoint informant activities to activities occurring more broadly (social relations).</i>
<i>Investigate the material, empirically observable events of peoples' lives.</i>	<i>Listen to people's "stories" of what practices and activities they engage in (DIAMOND in DeVAULT & McCOY, 2004, p.756).</i>
<i>Uncover the research problematic over time through the researcher's immersion in the field.</i>	<i>Be attentive to how informants describe the events of their lives. Listen for how people use institutional language and official or authoritative reasoning to explain events. People's accounts might actually be dissonant from what they experience and know.</i>
<i>Study features operating across multiple sites, and explore how these are connected through circulating texts and documents.</i>	<i>Ascertain the implicit and explicit social relations that shape informants' activities.</i>
<i>Identify the texts people use in their daily activities, and examine how they use them.</i>	<i>Find out about how texts organize what informants say and do (discursive organization).</i>
<i>Focus on how an informant's social location informs her/his knowing, and consider what the person can say from this position.</i>	<i>Develop understandings about how institutions function because this provides about social organization and power or ruling relations.</i>
<i>Cultivate understandings about the organization of institutional places from informants and texts. Researcher follows up on analytic clues of thread gathered in one interview or observational setting to the other.</i>	<i>Acquire understandings about how people use texts. Informants talk about peoples' work practices, and the researcher prepares to dialogue with and/or observe extra-local informants in later stages of fieldwork.</i>

Table 1: Characteristics of interviews using institutional ethnography [34]

Appendix 4: Western University Review Ethics Board Approval Notice



Research Ethics

**Western University Health Science Research Ethics Board
HSREB Delegated Initial Approval Notice**

Principal Investigator: Dr. Heloise Berman
Department & Institution: Health Sciences/Nursing, Western University

Review Type: Delegated
HSREB File Number: 108480
Study Title: Engaging Youth as Stakeholders in Mental Health System Transformation: An Institutional Ethnography of a Service Organization.

HSREB Initial Approval Date: November 23, 2016
HSREB Expiry Date: November 23, 2017

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Western University Protocol	Version 2 Received 2016/11/04	
Letter of Information & Consent	Appendix C: Adults Version 2	2016/11/04
Letter of Information & Consent	Appendix D: Youth Version 2	2016/11/04
Recruitment Items	Appendix G: Adult Recruitment flyer - Received 2016/09/12	
Recruitment Items	Appendix F: Youth Recruitment flyer - Received 2016/09/12	
Instruments	Appendix B: Interview Guide for Adults	2016/11/22
Instruments	Appendix A: Interview Guide for Youth	2016/11/22

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB 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 HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Ethics Officer, on behalf of Dr. Joseph Gilbert, HSREB Chair

Ethics Officer: Erika Basile ___ Nicole Kavali Grace Kelly ___ Katelyn Harris ___ Vicki Tran ___ Karen Gospat ___

Western University, Research, Support Services Bldg., Rm. 5150
London, ON, Canada N6G 1G9 T 519.661.3036 F 519.850.2466 www.uwo.ca/research/ethics

Appendix 5: Chatham-Kent Health Alliance Ethics Approval Notice



Alliance de Chatham-Kent pour la santé

Campuses	March 1, 2017
525 Margaret Ave. Wallaceburg, ON	Research Project Title: Engaging Youth as Stakeholders in Mental Health System Transformation: An Institutional Ethnography of a Service Organization
Mailing Address	Principal Investigator: Helene Berman (Co-supervisor for researcher) University of Western Ontario
	Sub-Investigator: Eugenia Canas (PhD student researcher)
Complexes	CKHA Reference No. 17FEB001 (please reference this number on all further correspondence)

The Research Project noted above, including:

- Research Application and Informed Consent form
- Declaration of Conflict of Interest
- Research Protocol

was reviewed by the Chatham-Kent Health Alliance Ethics Review Board (ERB).

Based on the documentation as presented, your research request was approved without conditions for a period of one year from the date of this letter

For your records, the Principal Investigator, Hospital Contact/Project Coordinator, or any member of the ERB that declared a conflict of interest was not involved in the voting process on this study.

A Status Report and/or Final Report is due within 30 days of the close of the research project, or when a request for annual renewal is submitted.

During the course of the research, no deviations from or changes to the protocol or consent form may be initiated without prior written approval from the ERB except when necessary to eliminate immediate hazards to the subject (e.g. increased risk), or when the changes involve only logistical or administrative aspects of the study (e.g. change in monitor, change in contact information). Expedited review of minor changes in ongoing studies will be considered.

All Serious Adverse Events must be submitted to the ERB in writing confirming the Principal Investigator has reviewed the documentation. If changes are required of the protocol as a result of the SAE, an explanation and additional documentation of the changes is required.

We wish you every success in your research.
Yours truly,

Lisa Northcott
Ethics Review Board

Appendix 6: Letter of Information and Consent for Youth



I

Letter of Information for Youth Participants Engaging Youth as Stakeholders in Mental Health System Transformation: An Institutional Ethnography of a Service Organization

Principal Investigator: Dr. Heleen Berman, Faculty of Health Sciences, Western University
Arthur Labatt Family School of Nursing, Room 2007, HSG/MJG 1045

You are invited to participate in a research study about the work of engaging youth as stakeholders in the design and delivery of mental health services. You are being asked to participate because of your involvement with the Youth Advisory Council with ACCESS Open Minds Chatham-Kent.

This study is concerned with the everyday experiences of engaging youth as stakeholders in the ACCESS Open Minds process. An institutional ethnography is a way of looking at how something that happens within an organization — in particular the work that people within it do — is connected to larger ways of organizing a system or describing a population. In this study, I am interested in describing how youth stakeholder engagement occurs within ACCESS Open Minds Chatham-Kent, in particular within the Youth Advisory Council, Operational and Leadership Group meetings.

My name is Eugenia ~~Carro~~, I am a PhD Candidate with the Health Information Science Program at Western University, and I am conducting this study as part of my doctoral dissertation. This work is supported by the supervision of Dr. Srividya ~~Reddy~~, Principal Investigator in ACCESS Open Minds, as well as Dr. Heleen Berman of the Faculty of Health Sciences at Western University, and Dr. Nadine ~~Walters~~ of the Faculty of Information and Media Studies at Western University. It is our hope that the information we learn through this research will help develop best practices for youth engagement within ACCESS Open Minds and in other programs of research and systems improvement dedicated to the health and wellbeing of youth.

If you take part in this study, you will participate in up to two one-hour individual interviews with me, to discuss the work of youth stakeholder engagement in ACCESS Open Minds Chatham-Kent. These interviews will take place at a time that is convenient to you, at a location within the Chatham-Kent Health Alliance' offices. We anticipate that up to 15 people from the professional team of Chatham-Kent Health Alliance will participate in these interviews; these include both youth members of the advisory council and adult professionals in the organization. Interviews will take place between the months of September 2016 and August 2017.

As part of this study, I have been welcomed to attend meetings of the Youth Advisory Council and working groups mentioned above, where you may be present. Many of the questions and

Discussion in our individual interviews may stem from my observations during these group meetings.

Your participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time. If you change your mind and decide that you do not want to take part in this research, you may do so at any time. If you decide to withdraw from the study, the information that was collected before you leave the study will still be used in order to help answer research questions. No new information will be collected without your permission.

There are no known risks for taking part in this research, but some of these conversations may prompt you to think deeply about your experiences in engaging youth through your professional practice. While you may receive no direct benefit from being in this study, information learned from it may facilitate improved engagement and collaboration with youth stakeholders, including the increased recognition the nature of this work, and of their ideas and contributions towards systems improvement. A summary of what we have learned from this research will be given to you when the study is over.

Confidentiality is an important value in this research. Anything you tell me will be held in the strictest confidence: your name will not be attached to any notes or comments, and all notes will be kept in a secure, locked location. If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published. All information that you give us about yourself will be kept confidential.

There are no conflicts of interest to declare related to this study. You do not waive any legal right by signing this form.

If you have any questions, please feel free to contact me or Dr. Helene Bertram at the contact information provided below. If you have any questions about the conduct of this study or your rights as a research participant, you may contact the Director, Office of Research Ethics, Western University, or email at:

This letter is yours to keep for future reference. Thank you for your interest.

Sincerely,

Eugenia 
Western University

Please initial to indicate you have read the document _____

Contact information:

Dr. Helene Bertram, Faculty of Health Sciences, Western University;
Eugenia  Faculty of Information and Media Sciences,



Consent Form

**Working with Youth as Stakeholders in Mental Health System Transformation:
An Institutional Ethnography of a Service Organization**

I have read the Letter of Information, have had the nature of the study explained to me. All questions have been answered to my satisfaction. I agree to take part in this study.

Participant's Name (please print)

Participant's Signature

Date (dd-mm-yy)

Substitute Decision Maker
(please print)

SDM Signature

Date (dd-mm-yy)

Person Obtaining Informed Consent
Name (please print)

Person Obtaining Informed Consent
Signature

Date (dd-mm-yy)



Appendix 7: Letter of Information and Consent for Adults



Letter of Information for Parent(s) or Guardian **Engaging Youth as Stakeholders in Mental Health System Transformation: An Institutional Ethnography of a Service Organization**

*Principal Investigator: Dr. Helene Berman, Faculty of Health Sciences, Western University
Arthur Labatt Family School of Nursing, Room 2007, HSB/H30 HAS*

I would like to tell you about a research study in which your son/daughter/ward has been invited to participate. This study is about engaging youth as stakeholders in the design and delivery of mental health services. Your son/daughter/ward is being asked to participate because of his/her/their involvement with the Youth Advisory Council with ACCESS Open Minds Chatham-Kent.

This study looks at the everyday experiences of engaging youth as stakeholders in the ACCESS Open Minds process. An institutional ethnography is a particular method of research. It looks at how something happens within an organization — in particular the work that people in it do. In this study, we seek to understand how youth engagement works to include young people's voices in the design of better mental health services.

My name is Eugenia Canas. I am a PhD Candidate with the Health Information Science Program at Western University, and I am conducting this study as part of my doctoral research. This work is supported by the supervision of Dr. Srividya Iyer, Principal Investigator in ACCESS Open Minds, as well as Dr. Helene Berman of the Faculty of Health Sciences at Western University, and Dr. Nadine Wathen of the Faculty of Information and Media Studies at Western University. It is our hope that the information we learn through this research will help develop best practices for youth engagement within ACCESS Open Minds and in other programs of research and systems improvement dedicated to the health and wellbeing of youth.

If your son/daughter/ward takes place in this study, they will participate in individual interviews with me, to discuss the experience of being a youth stakeholder in the ACCESS Open Minds Chatham-Kent. These interviews will take place at a time that is convenient to your son/daughter/ward, at a location within the Chatham-Kent Health Alliance' offices. As part of this study, I will also attend meetings of the Youth Advisory Council and other ACCESS Open Minds Chatham-Kent working groups, where your son/daughter/ward may be present. Many of the questions and discussion in our individual interviews may stem from my observations during these group meetings.

There are no known risks for taking part in this research, but some of these conversations may prompt your son/daughter/ward to think deeply about their experience as a youth stakeholder in ACCESS Open Minds. There are also several ways in which being in this study may be helpful to him/her/them. For many young people, just having a chance to talk about important experiences may be helpful. It is

also possible that, by talking about the process of being a stakeholder, your son/daughter/ward may understand it in new or different ways.

While your son/daughter/ward may receive no direct benefit from being in this study, information learned from it may facilitate improved engagement of youth as stakeholders, including the increased recognition of their ideas and contributions towards systems improvement. A summary of what we have learned from this research will be given to your son/daughter/ward when the study is over. A \$20 stipend will be provided in recognition of his/her/their time for each interview.

The participation of your son/daughter/ward in this study is voluntary. He/she/they may refuse to participate, refuse to answer any questions, or withdraw from the study at any time. If he/she/they decide(s) that you do not want to take part in this research, this is possible at any time. If your son/daughter/ward decides to withdraw from the study, the information that was collected before leaving the study will still be used in order to help answer research questions. No new information will be collected without permission.

Confidentiality is an important value in this research. Anything your son/daughter/ward tells me will be held in the strictest confidence: names will not be attached to any notes or comments, and all notes will be kept in a secure, locked location. If the results of the study are published, the name of your son/daughter/ward will not be used and no information that discloses identity will be released or published. All information will be kept confidential.

There are no conflicts of interest to declare related to this study. You do not waive any legal right by signing this form. This letter is yours to keep for future reference.

If you have any questions, please feel free to contact me or Dr. Helene Berman at the contact information provided below. If you have any questions about the conduct of this study or the rights of your son/daughter/ward as a research participant, you may also contact the Director, Office of Research Ethics, Western University, _____ or email at _____, Thank you for your interest.

Sincerely,
Eugenia Canas

Contact information:

Dr. Helene Berman, Faculty of Health Sciences, Western University, _____
Eugenia Canas, Faculty of Information and Media Sciences, _____

Please initial to indicate you have read the document _____



Consent Form

**Working with Youth as Stakeholders in Mental Health System Transformation:
An Institutional Ethnography of a Service Organization**

I have read the Letter of Information, have had the nature of the study explained to me. All questions have been answered to my satisfaction. I agree to take part in this study.

Participant's Name (please print)

Participant's Signature

Date (dd-mm-yy)

Person Obtaining Informed Consent
Name (please print)

Person Obtaining Informed Consent
Signature

Date (dd-mm-yy)



Appendix 8: Letter of Information and Consent for Parents



Letter of Information for Parent(s) or Guardian **Engaging Youth as Stakeholders in Mental Health System Transformation: An Institutional Ethnography of a Service Organization**

*Principal Investigator: Dr. Helene Berman, Faculty of Health Sciences, Western University
Arthur Labatt Family School of Nursing, Room 2007, HSB/H30 HAS*

I would like to tell you about a research study in which your son/daughter/ward has been invited to participate. This study is about engaging youth as stakeholders in the design and delivery of mental health services. Your son/daughter/ward is being asked to participate because of his/her/their involvement with the Youth Advisory Council with ACCESS Open Minds Chatham-Kent.

This study looks at the everyday experiences of engaging youth as stakeholders in the ACCESS Open Minds process. An institutional ethnography is a particular method of research. It looks at how something happens within an organization — in particular the work that people in it do. In this study, we seek to understand how youth engagement works to include young people's voices in the design of better mental health services.

My name is Eugenia Casas. I am a PhD Candidate with the Health Information Science Program at Western University, and I am conducting this study as part of my doctoral research. This work is supported by the supervision of Dr. Srividya Iyer, Principal Investigator in ACCESS Open Minds, as well as Dr. Helene Berman of the Faculty of Health Sciences at Western University, and Dr. Nadine Wathen of the Faculty of Information and Media Studies at Western University. It is our hope that the information we learn through this research will help develop best practices for youth engagement within ACCESS Open Minds and in other programs of research and systems improvement dedicated to the health and wellbeing of youth.

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There are no known risks for taking part in this research, but some of these conversations may prompt your son/daughter/ward to think deeply about their experience as a youth stakeholder in ACCESS Open Minds. There are also several ways in which being in this study may be helpful to him/her/them. For many young people, just having a chance to talk about important experiences may be helpful. It is

also possible that, by talking about the process of being a stakeholder, your son/daughter/ward may understand it in new or different ways.

While your son/daughter/ward may receive no direct benefit from being in this study, information learned from it may facilitate improved engagement of youth as stakeholders, including the increased recognition of their ideas and contributions towards systems improvement. A summary of what we have learned from this research will be given to your son/daughter/ward when the study is over. A \$20 stipend will be provided in recognition of his/her/their time for each interview.

The participation of your son/daughter/ward in this study is voluntary. He/she/they may refuse to participate, refuse to answer any questions, or withdraw from the study at any time. If he/she/they decide(s) that you do not want to take part in this research, this is possible at any time. If your son/daughter/ward decides to withdraw from the study, the information that was collected before leaving the study will still be used in order to help answer research questions. No new information will be collected without permission.

Confidentiality is an important value in this research. Anything your son/daughter/ward tells me will be held in the strictest confidence: names will not be attached to any notes or comments, and all notes will be kept in a secure, locked location. If the results of the study are published, the name of your son/daughter/ward will not be used and no information that discloses identity will be released or published. All information will be kept confidential.

There are no conflicts of interest to declare related to this study. You do not waive any legal right by signing this form. This letter is yours to keep for future reference.

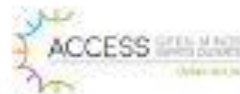
If you have any questions, please feel free to contact me or Dr. Helene Berman at the contact information provided below. If you have any questions about the conduct of this study or the rights of your son/daughter/ward as a research participant, you may also contact the Director, Office of Research Ethics, Western University, _____ or email at _____; Thank you for your interest.

Sincerely,
Eugenia Canax

Contact information:

Dr. Helene Berman, Faculty of Health Sciences, Western University.
Eugenia Canax, Faculty of Information and Media Studies, _____

Please initial to indicate you have read the document _____



Consent Form

**Working with Youth as Stakeholders in Mental Health System Transformation:
An Institutional Ethnography of a Service Organization**

I have read the Letter of Information, have had the nature of the study explained to me. All questions have been answered to my satisfaction. I agree to take part in this study.

Participant's Name (please print)

Participant's Signature

Date (dd-mm-yy)

Person Obtaining Informed Consent
Name (please print)

Person Obtaining Informed Consent
Signature

Date (dd-mm-yy)



Curriculum Vitae

Name: Eugenia Canas

Post-secondary Education and Degrees: University of Western Ontario
London, Ontario, Canada
1992-1996 B.A.

York University
Toronto, Ontario, Canada
1998-2000 M.A.

The University of Western Ontario
London, Ontario, Canada
2013-2019 Ph.D.

Honours and Awards: ACCESS Open Minds Doctoral Studentship
2016-2018

Related Work Experience

MINDS of London-Middlesex, Parkwood Institute of Mental Health, St. Joseph's Hospital.
August 2018 to present.

Centre for Research on Health Equity & Social Inclusion. Faculty of Health Sciences,
Western University. August 2015 to present.

National Youth Advisory Board Coordinator. Western University, Voices against Violence
project, January 2014 to December 2017.

Graduate Research Assistant. CIHR Research Trainee. Voices against Violence project,
January 2014 to December 2017.

Community of Practice Lead. mindyourmind, a program of Family Service Thames Valley.
November 2011 to August 2015.

Publications

Canas, E., Lachance, L., Phipps, D., & Birchwood, C. C. (2019). What makes for effective, sustainable youth engagement in knowledge mobilization? A perspective for health services. *Health Expectations*.

Noack, K., Elliott, N. B., Canas, E., Lane, K., Paquette, A., Lavigne, J. M., & Michalak, E. E. (2016). Credible, centralized, safe, and stigma--free: What youth with bipolar disorder want when seeking health information online. *UBC Medical Journal*, 8(1).

Elliott, N. B., Canas, E., Paquette, A., Johansen, K., Moore, C., Cundall, A., ... & Michalak, E. E. (2017). Youth engagement and community-based participatory research: The bipolar youth action project. *SAGE Publications Ltd*.