

RUNNING HEAD: COLLABORATION BETWEEN PROFESSIONAL CULTURES

**Collaboration between professional cultures:  
An investigation of families' experiences of inter-agency, collaborative mental health care**

By

Noah Moshe Pesach Spector

Dissertation submitted to the  
Faculty of Graduate and Postdoctoral Studies  
in partial fulfillment of the requirements  
for the degree of Doctorate of Philosophy in Educational Counselling

**Faculty of Education  
University of Ottawa**

© Noah Moshe Pesach Spector, Ottawa, Canada, 2017

### **DEDICATION**

I dedicate this dissertation to the memory of my grandparents, Bluma and Anshel Klodawsky, their struggles and bravery have forever shaped the family I am proud to be a part of. Also to the young people and their parents who participated in this research—their willingness to trust me and share their experiences is truly humbling. I hope the pages that follow honor their strength and persistence, often in the face of unbelievable adversity. Finally, to the service providers who gave their time and their opinions—I feel lucky to work with each and every one of you.

## ACKNOWLEDGEMENTS

This dissertation could only have been achieved with the assistance and support of people who have been there for me along the way, beginning many years before my Ph. D. journey started. To my parents, Aron Spector and Fran Klodawsky, thank you for providing and continuing to provide me a loving home base filled with intellect and support. To my brother, Gabriel Spector, thanks for being a calm voice of reason and an inspiration as you grow into a remarkable adult. To Helene, John, Simone, and Yasmine: I couldn't ask for a better Montreal family. To Simon Davidson, thank you for your encouraging words and your wisdom through the many years I have had the pleasure of working alongside you. To Cheryl Jacobson, thanks for helping me turn my relationship with my mind from a struggle with a mysterious foe to a comfortable relationship with a curious friend. To Sharon Bond, thank you for the numerous opportunities and supports you provided through my studies at McGill University and my work at the Jewish General Hospital. To Evie Cassell, Corrie Sirota, and Barbara Victor, of Agence Ometz, thank you for your invaluable lessons regarding community-based work. To Eric Jarvis and Michael Bond, thank you for your support and trust during my work in First Episode Psychosis. To David Paré, thank you for your accompaniment, encouragement and support throughout this long Ph. D. process. While we didn't cross the finish line together, my ultimate achievement would have been impossible without our work together. To members of the NTSG, thanks for your support and encouragement. I look forward to our continued work together. To Tracey Vaillancourt, thanks for your numerous contributions. From comprehensive exams to proposal defense, you challenged me to be the best writer I can be. To Phillippe Robaey and Helen Spenser, thank you for your interest and encouragement throughout this process. To Phillip Cheifetz, thank you for your support and friendship. To André Samson, *Merci pour tout!* To my past and present colleagues on the crisis team: Cindy Dawson (honorary), Lisa Cook, Kirstie Davis, Dion Sheppard, Patricia Smith, Heather Bragg and Janelle Comtois, thanks for your camaraderie and for putting up with my more "interesting" adverse reactions to this process. To my supervisors, Allison Kennedy, David Murphy, Josee Blackburn, Erin Kelly, Michelle Temple, Sophia Hrycko, Julie Perkins and Shanika Abraham, thank you for your understanding, encouragement and support. To the people who provided editorial support along the way—Robin Breger, Jennifer Rottman, and Martin Kellen, and Chris Fox, your feedback has helped me grow as a writer. To Ruth Kane, thank you for your help in crossing the finish

line. I have felt truly lucky for your clear-headedness and high expectations. Finally, to my committee members: Nicholas Ng-A-Fook, Cristelle Audet, Jessica Whitley, and my external examiner, Sally St. George, it has truly been an honour having you read my words and I am so appreciative of your insightful feedback and good wishes.

### **ABSTRACT**

Children's mental healthcare in Canada is undergoing a transition: instead of community- and hospital-based services working in parallel, there is a shift to increasing collaboration. When community- and hospital-based children's mental health service providers work together, differences in their philosophical approaches to treatment can be revealed. However, client experiences of these philosophical differences have not been explored. In this hermeneutic phenomenological study, I interviewed young people and their families who had lived experience of collaboration in a mid-sized Canadian city. I considered the results of these interviews with families who were new to treatment that was shared between hospital- and community-based services in light of literature on current initiatives in collaborative mental health care. I situated my results in the context of my on-going work as a service provider in this Canadian city alongside the reflections of service providers from the two organizations that were the focus of my research: the Children's Hospital and the Community Agency. I found that young people and their parents experience their care as being in a constant state of crisis when connections between these services are not explicit. In contrast, when connections are clear, families feel more able to manage their children's care. As well, service providers find that when explicit connections are forged between community-and hospital-based services, collaboration becomes more straightforward and is experienced as less hierarchal. The results of my research provide concrete tools, contextualized in the real worlds of current practitioners and clients, to help the future psychotherapists of Ontario work collaboratively towards supporting young people and their families who seek treatment for mental health diagnoses.

**TABLE OF CONTENTS**

|                                                                          |    |
|--------------------------------------------------------------------------|----|
| CHAPTER I: INTRODUCTION AND BACKGROUND.....                              | 1  |
| Beginnings .....                                                         | 2  |
| Initial Investigations.....                                              | 2  |
| The Integration of Collaboration .....                                   | 8  |
| Studying Interagency Collaboration and Continuity of Care .....          | 10 |
| CHAPTER II: REVIEW OF THE LITERATURE .....                               | 12 |
| Descriptions of Collaboration.....                                       | 12 |
| Descriptions of Continuity of Care .....                                 | 13 |
| Collaboration and Continuity of Care in Mental Health.....               | 14 |
| Studying Interagency Collaboration through Informational Continuity..... | 16 |
| Gaining Access and Moving through the System.....                        | 18 |
| Consistency of Information.....                                          | 24 |
| Specific Service Provider Actions .....                                  | 27 |
| Studying Collaboration and Continuity of Care .....                      | 32 |
| Methodological considerations. ....                                      | 32 |
| CHAPTER III: CONCEPTUAL FRAMEWORK.....                                   | 35 |
| Characterizing Experience .....                                          | 36 |
| Social Constructionism .....                                             | 36 |
| Application of a Social Constructionist position. ....                   | 37 |
| Professional Cultures .....                                              | 39 |
| Assumptions that Guide this Investigation .....                          | 41 |
| Resultant Social Practices .....                                         | 43 |
| Moving Forward .....                                                     | 45 |
| CHAPTER IV: METHODOLOGY AND METHODS.....                                 | 47 |
| Methodology: Hermeneutic Phenomenology .....                             | 47 |

|                                                                                         |     |
|-----------------------------------------------------------------------------------------|-----|
| Setting .....                                                                           | 50  |
| Ethics Processes .....                                                                  | 51  |
| Methods.....                                                                            | 51  |
| Participants and Recruitment .....                                                      | 51  |
| Data Collection .....                                                                   | 56  |
| Data Analysis .....                                                                     | 60  |
| Quality and Trustworthiness .....                                                       | 67  |
| A Contextualized Approach Grounded in Participant Experience .....                      | 67  |
| CHAPTER V: EXPLORATIONS OF INTERAGENCY COLLABORATION AND<br>PROFESSIONAL CULTURES ..... | 72  |
| Being Inducted into the Children’s Hospital .....                                       | 73  |
| Learning about the Community Agency .....                                               | 74  |
| Seeking Ethics Approval.....                                                            | 78  |
| Initial Focus Groups/Interviews.....                                                    | 81  |
| Meanings of Psychiatric Diagnosis.....                                                  | 82  |
| Meanings of Psychosocial Treatment .....                                                | 87  |
| Working Without a Map .....                                                             | 90  |
| Parents Connecting the Pieces of Care .....                                             | 92  |
| Signs of Collaboration .....                                                            | 94  |
| Synthesis of Stage I Findings.....                                                      | 97  |
| CHAPTER VI: NEW-TO-TREATMENT FAMILIES’ EXPERIENCES OF CONTINUITY OF<br>CARE.....        | 100 |
| Family Profiles.....                                                                    | 100 |
| Family 1: Catherine and Dave .....                                                      | 100 |
| Family 2: Elise and Nancy .....                                                         | 102 |
| Family 3: Pakhi, Kiran, and Raju.....                                                   | 104 |

|                                                                               |     |
|-------------------------------------------------------------------------------|-----|
| Investigating Informational Continuity.....                                   | 107 |
| First Interviews .....                                                        | 108 |
| Three-Month Follow-Up Interviews.....                                         | 113 |
| Professional Cultures .....                                                   | 121 |
| Summing Up .....                                                              | 124 |
| CHAPTER VII: STAGE III SERVICE PROVIDER REFLECTIONS .....                     | 127 |
| Service provider reflections on families' stories of seeking connections..... | 130 |
| Service provider reflections on families managing care.....                   | 132 |
| Professional Cultures .....                                                   | 134 |
| Service provider reflections on professional cultures.....                    | 135 |
| CHAPTER VIII: DISCUSSION AND CONCLUSIONS.....                                 | 140 |
| Discussion of Results.....                                                    | 141 |
| Current Developments in River City's Mental Health Services.....              | 144 |
| Language Use.....                                                             | 146 |
| Conclusion .....                                                              | 148 |
| Implications.....                                                             | 148 |
| Implications for counsellor/psychotherapist training.....                     | 148 |
| Implication for counsellors engaging in interagency collaboration.....        | 149 |
| Implication for service users who are receiving collaborative care.....       | 150 |
| Limitations .....                                                             | 151 |
| Recommendations for Future Research.....                                      | 151 |
| Summary and Conclusions .....                                                 | 152 |
| REFERENCES .....                                                              | 153 |
| APPENDIX A: MODIFICATIONS TO ORIGINAL RESEARCH DESIGN .....                   | 171 |
| APPENDIX B: INTERVIEW GUIDES .....                                            | 172 |
| APPENDIX C: CONSENT AND ASCENT FORMS.....                                     | 178 |

|                                                                                       |     |
|---------------------------------------------------------------------------------------|-----|
| APPENDIX D: SELECTED RECRUITMENT PRESENTATION SLIDES .....                            | 197 |
| APPENDIX E: PARENT FOCUS GROUP SUMMARY .....                                          | 199 |
| APPENDIX G: THEMES, CODES AND REPRESENTATIVE QUOTES FROM STAGE II<br>INTERVIEWS ..... | 210 |
| APPENDIX H: INITIAL RESULTS PRESENTATION SLIDES .....                                 | 214 |

**LIST OF TABLES**

|                                                                                        |    |
|----------------------------------------------------------------------------------------|----|
| Table 1: Stage I parents' demographic characteristics .....                            | 64 |
| Table 2: Stage I youth demographic characteristics .....                               | 65 |
| Table 3: Stage II parents' demographic characteristics .....                           | 66 |
| Table 4: Stage II youth demographic characteristics .....                              | 66 |
| Table 5: Stage III community-based service providers' demographic characteristics..... | 67 |
| Table 6: Stage III hospital-based service providers' demographic characteristics.....  | 67 |

**LIST OF FIGURES**

|                                                                           |     |
|---------------------------------------------------------------------------|-----|
| Figure 1: Data collection and analysis listed by stage.....               | 68  |
| Figure 2: Stage I & II families' entries into mental health services..... | 139 |
| Figure 3: Stage I & II families' experiences of continuity of care.....   | 140 |
| Figure 4: Discursive positions of families in Stages I & II.....          | 141 |

## **LIST OF ABBREVIATIONS**

ADBC: The Children's Hospital's ADHD and Disruptive Behaviour Disorders outpatient clinic

ADHD: Attention Deficit Hyperactivity Disorder

MD: Physician

OT: Occupational Therapist

Psych: Psychologist

REB: the Children's Hospital Research Ethics Board

REC: The Community Agency's Research Ethics Committee,

SW: Social Worker

YFCS: The Community Agency's Youth and Family Counselling Service

## CHAPTER I: INTRODUCTION AND BACKGROUND

Hospital- and community-based children's mental health service providers practice in different philosophical environments, yet increasingly they share the care of clients. In this first chapter, I detail how my research into the shared practices of these two groups evolved from an exploration of contrasting service provider perspectives on the diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) to a focus on *interagency collaboration* in mental health care in the context of professional cultures, as experienced by young people and their families, in River City,<sup>1</sup> the mid-sized Ontario city that is the locus of this investigation. During this dissertation, I learned that collaboration between hospital- and community-based children's mental health service providers in River City is of growing importance in the context of increasing demand for integrated mental health services. I also learned that very little literature exists regarding the experiences of the young people and their families who use community- and hospital-based services concurrently.

Therefore, I designed a study based upon the assumption that experience is best understood with attention to the context within which it is investigated, what others call hermeneutic phenomenology. I describe the evolution of my study design to assist readers in understanding my point of view and the factors that may have influenced my perspective, which is part of this context. This type of description is consistent with the epistemological position of social constructionism, which suggests that knowledge is generated within speech communities and in conversations with others. When speaking from a social constructionist<sup>2</sup> (or constructivist) position, I pay particular attention to the ideas (or discourses) that predominate in guiding specific communities and conversations. In this dissertation, I focus on communities of professionals who work in either a community- or a hospital-based setting and on conversations related to mental health treatment as recounted by the young people and their families who receive care shared between these professionals. In this first chapter, I recount the story of how I came to ask the questions with which my dissertation engages, demonstrate the importance of these questions through a vignette, briefly describe the concepts I use in this investigation and conclude with an outline of the chapters to follow.

---

<sup>1</sup> I use a pseudonym for the name of this city to protect the anonymity of the clients and organizations I studied.

<sup>2</sup> Following Paré (1996), I use the term social constructionism which according to his argument subsumes the term *social constructivism* in focusing on the investigator and research participants communally interpreting the "text" of experience. I will further elucidate this stance in my Conceptual Framework.

### **Beginnings**

This journey began when I applied to the University of Ottawa's newly created PhD program in Educational Counselling, where I hoped to build upon my previous explorations concerning different treatment perspectives on ADHD during my Masters of Social Work degree.<sup>3</sup> Therefore, in my original application to the University of Ottawa, I proposed exploring the divide between a biomedical psychiatric and a social constructionist perspective through specific questions. My tentative questions reflected an assumption that counsellors adopting/practicing from a social constructionist viewpoint and psychiatrists from a primarily biomedical background inhabited different professional cultures that worked in different spheres within the mental health care constellation. Specifically, my original research focus was care for children struggling with disruptive acting out and impulsive behaviours which, when impairing their functioning in at least two areas of life, comprises clinical criteria for ADHD as specified in the Neurodevelopmental Disorders section of the American Psychiatric Association's, fifth and most recent edition of the Diagnostic and Statistical Manual (DSM-5) (American Psychiatric Association, 2013). My initial research questions built upon my understanding of the development of psychiatric classifications and my study of the application of social constructionist theory to psychotherapy as described by Narrative therapists (Burr, 2003; Gergen, 2010; White & Epston, 1990).

### **Initial Investigations**

To address my tentative research questions, I began engaging with the agencies from which I hoped to recruit participants for my research: the Community Agency's Youth and Family Counselling Service (YFCS), many of whose practitioners were influenced by social constructionist ideas (Paré, 2009), and the Children's Hospital's ADHD and Disruptive Behaviour Disorders outpatient clinic (ADBC), where I expected to find more adherents to the biomedical model.<sup>4</sup>

My underlying assumptions characterized the Community Agency's YFCS as a team that was predominantly community-based; that is, guided by a focus on practitioners working alongside service users<sup>5</sup> to understand the social conditions of mental health problems, and

---

<sup>3</sup> These explorations culminated in a theoretical article (Spector, 2008) that delineated mainstream clinical perspectives and perspectives informed by sociological (commonly referred to as social constructionist) critiques about ADHD diagnosis and treatment.

<sup>4</sup> Both *Community Agency* and *Children's Hospital* are pseudonyms.

<sup>5</sup> In this dissertation, I use the terms *client* or *service user* to refer to users of mental health services.

reinforcing the competencies these clients brought to mental health treatment. On the other hand, I characterized the Children's Hospital ADBC, as largely guided by the biomedical model of mental illness with practitioners working to identify and medicate client deficits, which are viewed as independent of these clients' social contexts.

However, during my engagement with the Community Agency's YFCS and the Children's Hospital ADBC, I discovered that, despite the different backgrounds of members of these teams, the practices of clinicians in these agencies were not as polarized as I had anticipated. Rather, my experience of the current state of ADHD treatment in River City was that it followed the dominant discourse of ADHD as a neurological condition that was treated, primarily, with stimulant medications (Pliszka, 2007). I learned that family physicians and paediatricians were the primary service providers for young people diagnosed with ADHD, and that these primary care providers sought input from psychiatric and community-based professionals as needed. I also learned, in feedback from the Community Agency on the research design I initially proposed, that young people with an ADHD diagnosis infrequently accessed services where service providers collaborated with the Children's Hospital and that Community Agency service providers who worked with ADHD diagnoses integrated biomedical understandings into their treatments.

Thus, I understood that a strict comparison of two distinct approaches to ADHD, informed by two different knowledge bases, was not feasible given the recent community integration of the medical perspective necessitated by an increased focus on collaboration with hospital-based services. However, despite the dominance of the biomedical discourse regarding ADHD, practitioners at both the Community Agency and the Children's Hospital also often drew from both biomedical and social constructionist perspectives. Therefore, I became interested in how practitioners with different views on the origins of mental health difficulties worked together in the field.

In describing clinicians from different perspectives working together, I have chosen not to depict non-medical approaches as subversive acts against dominant medical discourses (e.g., Bradford, 2009; Paré, 2009; Strong & Gaete, 2012), because this characterization promotes division rather than collaboration, and would not be useful to the diversity of practitioners, who are being encouraged, increasingly, to work collaboratively. My experience in the field has reinforced this belief; I have found that much more productive relationships emerge when I seek different perspectives on a situation instead of dismissing positions that counter mine. For

instance, when working as a psychiatric research coordinator and triage clinician, I found a nuanced knowledge of psychiatric terminology and diagnoses was extremely helpful in advancing the importance of a social perspective regarding clients' experience of psychoses. Similarly, in a placement at the Community Agency, knowledge of psychiatric parlance helped me to better communicate with professionals from other agencies. Finally, in my current work as a psychiatric emergency crisis intervention worker at the Children's Hospital, such knowledge helps justify my social interventions within the context of the emergency medical department.

The distinction between arguing for one truth and holding multiple truths in tension is an important one in social constructionist epistemology, which suggests that researchers not focus on finding "the truth," but rather depict various perspectives on knowledge in the context of where this knowledge was created and interpret this knowledge alongside participants in their research (Haene, 2010). Therefore, I chose to inquire into how client families experienced the collaborative work of mental health professionals working in agencies with different philosophical backgrounds (i.e., hospital- and community-based). This newfound focus, in combination with the realization that ADHD was now treated predominantly by family physicians, encouraged me to expand my investigation to include other psychiatric disorders commonly diagnosed in adolescence. Because shared treatment of these disorders is a recent development (Madsen, 2014), I felt it was important to understand the evolution of shared treatment in River City, focusing on how the two agencies under investigation have come to collaborate. Building on my experience with these two agencies, I provide an example, gleaned from my experience in the field and my research findings, to demonstrate how families may experience collaborative care between agencies. Following this example, I will describe how I came to focus upon the ideas I consider in this dissertation.

To demonstrate interagency collaboration and professional cultures, and how I will apply these conceptual terms, I now describe a fictional vignette of a mother and son, whom I refer to as James and Heather, that outlines their initial experiences of moving between the Children's Hospital and the Community Agency. This vignette is based on my years of clinical experience in the field and I include it to give the reader a sense of the terms used in this document. James is a 12-year-old boy who lives with his mother, Heather, in a small two-bedroom apartment in an economically depressed area in the west end of River City. For a number of years, James has struggled with his moods. In addition to James eating substantially less than usual, Heather recently discovered that James had been cutting himself. When Heather asked James about his

cutting, James disclosed that he was having thoughts of killing himself. Heather was understandably concerned about these thoughts and, not knowing what else to do, brought James to the Emergency Department of the Children's Hospital.

Heather and James noticed during their visit to the Children's Hospital Emergency Department that the person they saw there, Kathleen, focused on addressing anything that put James at immediate risk and was very intent on informing the family about possible next steps. After talking about this impression a bit, James and Heather commented on how they had been asked many times about the thing they needed dealt with right away and observed that, while Kathleen had listened to their story, she was predominantly focused on the most troubling symptoms. They also noticed that she suggested many things, such as long-term counselling and a possible consideration of psychotropic medication, that they could not address fully in their visit. Kathleen had written down her recommendations and given the family more information on the symptoms (i.e., cutting and suicidal thoughts) about which they had expressed concern. James and Heather left their visit to the Children's Hospital understanding that James needed to explore more about the death of his father, two years past, to see their family doctor about possible medication, and to go to the Community Agency's walk-in clinic to pursue further counselling. James and Heather were not previously aware of the Community Agency.

After visiting their family doctor, who prescribed a medication and sent a referral to the Children's Hospital for further psychiatric services, Heather and James subsequently visited the Community Agency's walk-in clinic. During their visit to the walk-in clinic, they noticed many bright posters with pictures of young people on the wall. James and Heather talked about how these surroundings were a contrast to the busy Children's Hospital Emergency department, with its noisy, yet clinical and sterile environment. They also noticed that the counsellor they met with at the Community Agency was concerned with getting James' whole story, whereas at the Children's Hospital Kathleen had mostly focused on symptoms and risk. This counsellor, Shirley, was concerned about helping James and Heather with their immediate problem—something she wrote about in a letter to the family following the visit—but she also asked about the family's wider circumstances (e.g., finances, school grades).

Unfortunately, Shirley did not have any information about James and Heather's previous visit to the Children's Hospital and because of this lack of information asked many similar questions as they were asked during their Emergency Department visit. Shirley apologetically explained that unless Heather and James specifically requested that this information be shared,

neither the Children's Hospital nor the Community Agency staff made it standard practice to communicate with each other. James and Heather told Shirley about James' father, Frank, who had died in a car accident when James was 10. Following this visit, Shirley told James that he could call the Community Agency's crisis line for further support while he waited for a long-term counsellor. During a moment of feeling overwhelmed, James called the crisis line and was able to re-connect with Shirley for a few more sessions. Shirley continued to follow James for another two months until the Community Agency assigned him a more permanent counsellor, Maurice. In their first session together, Maurice, James, and Heather discussed their previous work with Shirley, and they also discussed how they would work together in the future.

Following four months of James working with Maurice and taking the medication prescribed by his family doctor, Heather received a call from the Children's Hospital. The receptionist told Heather that James had an appointment with a Child and Adolescent psychiatrist, Dr. McAllister the following week. When Heather and James arrived at their appointment, they noticed the waiting room was crowded, and they had to wait a bit for their appointment. When they met with Dr. McAllister, they once again had to repeat their story. Dr. McAllister had the report from the time that they had visited the Emergency Room and the brief referral from their family doctor. Heather and James thought that these documents gave Dr. McAllister some idea of what had gone on before. However, Heather insisted that Dr. McAllister also speak to Maurice to get more information about what had happened at the Community Agency. Dr. McAllister agreed and had both Heather and James sign a consent form so that he could communicate with Maurice. Dr. McAllister also made recommendations around James' medication and scheduled a follow-up appointment for a month later.

The above example provides brief glimpses into the professional cultures of the Children's Hospital and the Community Agency and how information flows between these organizations. As James and Heather noted in their initial visit to the Children's Hospital, the person they met focused on their immediate circumstances, gave them advice, assessed risk, and made only informal referrals. In other words, the family themselves had to initiate the next step in their treatment journey. James and Heather's subsequent experience of the Community Agency also demonstrates aspects of its professional culture: a more welcoming environment and a focus on the family's wider circumstances such as discussing the death of James's father,

finances, and school grades. Moreover, Shirley strengthened their connection by writing a letter<sup>6</sup> that the family could refer to after their visit. The Children's Hospital's focus on immediate risk (i.e., risk assessments) and the Community Agency's focus on keeping families engaged in treatment (i.e., accessible clinics, 24-hour crisis line) are parts of these agencies' professional cultures. In regards to interagency collaboration, I note that the clinician at the Children's Hospital did not take steps to pass information on to the Community Agency nor did the Community Agency transmit information to the Children's Hospital. In James and Heather's experience, although they worked on similar concerns, the Community Agency and the Children's Hospital had no arrangements to share information to facilitate movement between the two agencies.

James and Heather's story shows breaks what researchers describe as *continuity of care* (Haggerty et al., 2003). The construct of continuity of care is important because the system for delivering children's mental health services has evolved considerably in recent years as separate systems of hospital- and community-based support are being integrated into systems of care for children and their families. Whereas continuity of care used to be achieved mostly through delivery of service within the walls of hospitals or other large institutions, authors now use the construct continuity of care to characterize interactions between a variety of services in the community, and, as a result, an individual client or client system's experiences of collaboration between diverse practitioners (Adair et al., 2003). The first dimension of the concept of continuity of care, *informational continuity*, which I focus on in this dissertation, involves the exchange of clinical data, and extends to the families' understanding (observed through noting their descriptions) of service providers' knowledge of their concerns (Tobon, Reid, & Goffin, 2014). In the case of Heather and James, a lack of informational continuity resulted in the family having to repeat their story in their initial interactions with both Shirley (Community Agency) and Dr. McAllister (Children's Hospital). Moreover, Heather had to insist that Dr. McAllister work with Maurice. In these examples, the family experienced breaks in informational continuity between services offered by different agencies.

Such breaks may proceed from organizational policies as well as from the specific styles of individual clinicians. In Heather and James's case, attention to smoothing transitions between

---

<sup>6</sup> Writing a therapeutic letter is a practice used by counsellors to summarize sessions for service users. These letters often include summaries of past work and recommendations for accessing further supports (Pare, Rombach, & Sori, 2003).

agencies by simplifying information sharing might have reduced the need for Heather and James to tell their stories so many times. In addition, the fact that this family system engaged with so many different clinicians made it difficult for an individual clinician to maintain a relationship with them over time.

In this dissertation, I analyse how families characterize interagency collaboration and the informational dimension of continuity of care. I conduct this analysis by recounting the ways that young people and their families described their experiences of interagency collaboration and continuity of care in the context of the professional cultures of the Children's Hospital and the Community Agency. I also discuss reflections by service providers on my initial analysis to supplement my discussion of findings. I will describe these two agencies in further detail in my methodology chapter (Chapter IV). To further frame this investigation I will now describe the evolution of thinking regarding the concepts I have chosen to focus on in this investigation including collaboration, continuity of care, and professional cultures.

### **The Integration of Collaboration**

One use of the concept of collaboration has been as a descriptor for therapies informed by social constructionist ideas (Paré, 1995; Paré & Lerner, 2004). Interprofessional collaboration has also received significant interest in the field of healthcare, where researchers have been interested in how persons from diverse professional backgrounds work together effectively to better assist their patients (B. Davis & Sumara, 1997; Klein, 1996). As I elucidate further in Chapter II, interprofessional collaboration is found both within agencies (co-located collaboration), and between agencies (interagency collaboration). Co-located collaboration has been well-documented in the literature (Asarnow et al., 2005; Richardson et al., 2014; Richardson, McCauley, & Katon, 2009). Nonetheless, such interagency collaboration has been studied, primarily, as a comparison to co-located collaboration, and not in itself been well-researched. A study of collaboration literatures and my increased awareness of collaboration in the field (i.e., between the Children's Hospital and the Community Agency) highlight the potential benefits of applying a theoretical understanding of collaboration in a therapeutic setting to the reality of family experiences of their practitioners working together.

**A focus on collaboration and continuity.** What initially drew me to the idea of collaboration was the social constructionist idea of language being constitutive of reality. The idea that communities have the ability to create and change realities (Anderson & Goolishian, 1988) underlies much of the social constructionist therapy canon. I connected this idea of

realities unique to particular communities to the practice of interagency collaboration by recognizing that young people treated collaboratively by service providers from different backgrounds were exposed to the different communities of these service providers. I, therefore, wondered how these young people and their families experienced these different communities in the course of their treatment for a psychiatric diagnosis. My study explores how diverse persons (i.e., young people, their families, and service providers) work communally to coordinate their actions towards a preferred reality (i.e., the resolution of mental health difficulties). The idea of communal reality construction has gained common acceptance within various counselling approaches inspired by social constructionist ideas such as Solution Focused Therapy (Gingerich & Eisengart, 2000), Narrative Therapies (Besley, 2002; Combs & Freedman, 2012; Lerner, 1996; M. White, 2007; M. White & Epston, 1990), and Collaborative Language Systems (Anderson & Gehart, 2007).

I began to see social constructionist ideas applied in therapy and in psychotherapy research (Haene, 2010; Strong & Gale, 2013) as potentially key tools for exploring family experiences of collaborative practice, which encouraged me to think that they would be useful to my exploration of how a client's multiple practitioners contributed significantly to that client's experience of their presenting problems. Therefore, I became interested in studying the context of interagency collaboration using ideas that had been applied to collaboration in individual counselling sessions. Although my interest in the person-to-person level of collaboration was the catalyst to my change of focus, my own working experience of the context for this research also influenced my changed focus.

This context involved a mental health system for young people that was changing rapidly towards a model wherein agencies increasingly shared client care, necessitating interagency collaboration. In addition, significant recent social policy interests and investigations have also focused on service users' experiences of various facets of shared treatment by multiple clinicians within health systems, or continuity of care (Haggerty et al., 2003), as discussed above. In Chapter II, I describe the various conceptualizations of both interagency collaboration and my use of a specific dimension of continuity of care, informational continuity, and I also discuss investigations guided by these concepts and their application to young people's mental health care in Canada. These ideas and investigations are key to my social constructionist study, which focuses on communities that enact practices of interagency collaboration and continuity of care.

**My use of professional cultures.** I provide further context to my investigation into families' experiences of care shared between two agencies by using Pippa Hall's (2005) concept of *professional cultures*, which she argues is essential to exploring how practitioners with varied backgrounds work together. Mental health practitioners who work in separate agencies and have distinct professional backgrounds may have very different ideas of the origins of mental health difficulties. In particular, some may have social explanations of how these difficulties develop while others subscribe to biomedical explanations. Therefore, in this dissertation, I argue for the consideration of unique professional cultures in my exploration of young people and their families' experiences of moving between hospital-based services provided by the Children's Hospital and community-based services provided by the Community Agency.

### **Studying Interagency Collaboration and Continuity of Care**

The focus of this study is young people and their families' experiences of interagency collaboration and continuity of care in the context of changing relationships between two agencies with distinct professional cultures. I used the concepts of interagency collaboration and continuity of care as specific constructs to track family experiences across the different professional cultures represented by the Community Agency and the Children's Hospital in River City. In Chapter II, I describe the constructs of interagency collaboration and continuity of care in greater depth, and summarize relevant previous research before I demonstrate how I combined these concepts; I then list my research questions. In Chapter III, I summarize the conceptual framework of this dissertation, a social constructionist perspective on professional cultures that I used to investigate these research questions. In Chapter IV, I describe how I used hermeneutic phenomenology in both collecting and organizing my research data reflecting families' experiences of interagency collaboration and continuity of care in the context of professional cultures.

I present my research findings in Chapters V and VI. In Chapter V, I reflect on my experiences of the Community Agency and the Children's Hospital to provide descriptions of these agencies' respective professional cultures. I use my reflections, my review of the literature, and the conceptual framework discussed in Chapter III to frame my analysis of interviews with young people and their families who had had significant lived experience of care shared between the Community Agency and the Children's Hospital. In Chapter VI, I build upon these results of my explorations of interagency collaboration. I describe how I used lessons learned in my first stage of data collection, to frame the findings resulting from my analysis of interviews with new-

to-treatment families regarding their experiences of continuity of care. Finally, in Chapter VII, I discuss my analysis of the reflections of the research respondents featured in Chapter VI and of the service providers who had been involved in similar collaborative care relationships. I conclude this exploration by comparing my results and conclusions to findings of parallel investigations, and consider present service reorganizations in River City in light of my findings.

## **CHAPTER II: REVIEW OF THE LITERATURE**

In the previous chapter, I described the background of this study regarding young people and their families' experiences of mental health treatment as shared between the Children's Hospital and the Community Agency in River City. As noted, I use two important constructs to guide my investigation: interagency collaboration and continuity of care. Following Brown (1995), I use the term "construct," as it is used within medical sociology, to acknowledge the wide variety of definitions for both continuity of care and interagency collaboration. Of these definitions, I use interagency collaboration to describe providers working together across different organizations, and continuity of care to comprise specific dimensions of the experience of clients receiving mental health care from professionals collaborating across diverse organizations. I provide a brief history of how the scholarly literature presents interagency collaboration and continuity of care before defining and situating their use in my investigation. I conclude the chapter with a methodological critique of the studies I reviewed, which leads to a statement of the research questions that guide my investigation.

### **Descriptions of Collaboration**

The construct of interagency collaboration describes part of the broader movement towards integration of community- and hospital-based health and social services known as interprofessional collaboration. In the Canadian health system, interprofessional collaboration between agencies is increasingly important. For example, Romanow (2002), in a report to the Canadian Senate, highlights the importance of interprofessional collaboration and the equitable distribution of health services to facilitate service users returning swiftly to community services following hospitalization. Romanow (2002) describes the need for all health service professionals to work in conjunction with other professionals, across agency boundaries, to the greatest extent possible within their scopes of practice. He also encourages increased attention on professionals from different backgrounds working together to ensure that service users can access needed services efficiently.

In line with Romanow's findings, Osher (2002) characterizes interagency collaboration as service providers from different agencies working together to pursue common goals. He contrasts collaboration with cooperation, which he defines as agencies interacting more informally (i.e., through unplanned contacts). Osher (2002) also defines coordination as staff from different agencies working together in the interests of a client, but outside of a specific treatment plan involving a particular goal. San Martín-Rodríguez, Beaulieu, D'Amour, and

Ferrada-Videla (2005), in a large-scale review, define the act of collaboration in health care as “the idea of sharing that impl[ies] collective action oriented toward a common goal, in a spirit of harmony and trust” (p. 116). Regarding this collective action, San Martín-Rodríguez et al. (2005) argue that current models of interprofessional collaboration provide little basis for integrating the perspectives of service users—a key party in collaborative healthcare. Emphasizing the importance of service users, Peek and the National Integration Advisory Council (2011) in a recent review of terms used in collaborative healthcare emphasize the importance of service users’ perspectives on treatment that results from collaborative efforts between service providers.

This dissertation focuses on service users’ experience of interagency collaboration where professionals, working concurrently in child and adolescent mental health care, from different backgrounds collaborate between hospital- and community-based services. I focus specifically on what Poland et al. (2005) describe as hospital-community collaboration—an area of study that these authors describe as under-researched in the current literature. Authors writing on interagency collaboration, as an aspect of interprofessional collaboration, focus on the specific work done between collaborating professionals from different agencies. Continuity of care refers to specific aspects of families’ experiences of health treatment systems, in this case, mental health treatment systems, which I address next.

### **Descriptions of Continuity of Care**

Over the past 10 years, a significant effort has been made toward clarifying the concept of continuity of care in general health care (Haggerty et al., 2003; Reid, Haggerty, & McKendry, 2002), and specifically in mental health care (Adair et al., 2003). Authors use the construct of continuity of care to characterize the end results of work shared by service providers, and to refer to specific aspects of service users moving between, and relating to, various service providers (Bachrach, 1981; Reid, Haggerty, & McKendry, 2002). In the literature related to medical problems, continuity of care often refers to a medical home, or to a particular practitioner whose relationship with a particular patient continues beyond the time when the patient is actively receiving treatment. In mental health care, contemporary scholars use continuity of care to describe a relationship with a particular group of service providers coordinated by a common purpose and plan. This coordination often includes social service agencies in addition to traditional healthcare services (Haggerty et al., 2003). More recently, the construct has been used to characterize client experiences of service providers working together to offer more useful perspective as an alternative to terms that measure only administrative needs. In this dissertation,

I use the construct of continuity of care to characterize client experiences of interagency collaboration, a type of interprofessional collaboration, in children's mental health care.

### **Collaboration and Continuity of Care in Mental Health**

Recent work on mental health services has demonstrated a need for increased interprofessional collaboration. For example, a Senate report, produced by the Kirby Commission (Kirby & Keon, 2006), identified mental health services as particularly fragmented. The Kirby Commission recommended that mental health services in Canada become increasingly community-based and recovery-oriented, rather than focused on traditional, hospital-based treatments.

An offshoot of the work of the Kirby Commission, which later culminated in a 2006 report, the Canadian Collaborative Mental Health Initiative (CCMHI), proposed a shift to a model of mental health services centred on the needs of service users (Gagné, 2005). The CCMHI describes collaborations between service providers that followed from the needs of a particular service user, not from the specific mandates of individual agencies, as previously practiced. Gagné (2005) described the CCMHI model, and particularly its focus on organizing care around the service user, as addressing many of the shortcomings in work between agencies, as highlighted by Romanow (2002) and later by Kirby and Keon (2006) who described Canadian mental health services as not sufficiently focused on the needs of service users. Authors of the CCMHI proposed an organizing structure for interprofessional collaboration based on the needs and experiences of the service user, a focus that has evolved from broad trends in North American mental health systems and the resultant contemporary construct of continuity of care.

In regards to the use of continuity of care in the context of these broad trends, Adair et al. (2003) detail the evolution of the use of this construct in mental health care. These authors report how continuity of care has been used to characterize service users' experiences of health service systems for the last 50 years. They describe how continuity of care originated during the 1960s in measures of re-admissions to, and transfers between, hospitals at a time when treatment for mental health difficulties was largely hospital-based.

Adair et al. (2003) report how continuity of care came to inform the use of case management in the 1970s. Following the transfer of mental health treatment from hospital- to community-based care (deinstitutionalization) in the 1970s, researchers used the construct to characterize post-hospital community contacts between service providers and their clients. Finally, in the 1980s and 1990s, continuity of care was used to characterize relationships

between patients and service providers, in addition to measuring patients' experiences of movement through the mental health care system. Adair et al. (2003) present further research beginning in the 1990s that broadened the scope of continuity of care in mental health services, and note that a variety of definitions that informed various measures of this construct continued to exist.

The authors conclude by demonstrating how, in the early 2000s, no authoritative definition of continuity of care existed, and they also argue that existing definitions were limited because they did not include continuity of care from the patient's perspective. Researchers in recent investigations use specific definitions to inform measures of continuity of care to describe child and youth experiences of mental health treatment in Ontario (Tobon, Reid, & Goffin, 2013). Researchers have built these measures based on extensive studies of adults with severe mental health difficulties (Adair et al., 2005; Joyce et al., 2004; Ware, Tugenberg, Dickey, & McHorney, 1999). The use of specific dimensions of continuity of care complements a focus on interprofessional collaboration in mental healthcare for children and youth.

***Interprofessional collaboration in children's mental health care.*** In arguing for increased interprofessional collaboration in child and youth mental health care, Spenser et al. (2006) build on the CCMHI's work to demonstrate that mental health services directed at young people and their families differ from adult mental health services: they require connections between different elements of the health and social care system such as services for families, education services and individual services for youth. These authors argue that current fee structures within public health insurance are insufficient to support the multi-disciplinary work across agencies that would be required to provide optimal mental health care to young people. Spenser et al. (2006) claim that as a consequence, services which transcend agency boundaries (i.e., community organizations and hospitals), such as outreach and service coordination, suffer from a lack of financial support.

Kutcher and McLuckie (2010, 2013), creators of the Evergreen framework to improve the organization of services for children and youth, argue for specific strategies to encourage collaboration between mental health service providers to ensure ease of access, choice, and connection between child and youth mental health services housed in different agencies. The creation of social policy initiatives such as Evergreen and the CCMHI have resulted in further work in various provinces to realize better connections between child and youth mental health services.

Boydell, Bullock, and Goering (2009) examine the complexity of relationships between service providers undertaking interagency collaboration in Ontario child and youth mental health and characterize collaboration as a combination of team efforts that address clients' perspectives while working towards a synergy of perspectives between clients and multiple service providers. Their review emphasizes previous empirical work, which details both the increased efficacy of collaboration and the inherent risks of confusion and stagnation in case of a poor fit between the perspectives of those involved (Huxham, 2003; Huxham & Vangen, 2004).

Boydell et al. (2009) also provide an important distinction, within interagency collaboration, between vertically and horizontally integrated children's mental health systems. In vertical integration, all organizations (i.e., both hospital- and community-based) are brought together under central management, and these organizations share processes to respond to a client's needs along a continuum of care. A continuum of care refers to a range of service from a single encounter with one agency to long-term therapeutic work involving multiple agencies. In comparison, Boydell et al. (2009) describe horizontal integration as collective efforts between separate organizations that form links and share resources as appropriate. The focus of my research is horizontal integration between a children's hospital and a community agency in River City.

Boydell et al. (2009) note the lack of research on the experiences of young people and their families within integrative mental health systems. These authors demonstrate that in the literature on systems integration, service users' views are generally not included. Boydell et al. (2009), in particular cite the paucity of service user involvement in re-designing systems to provide care for children, youth, and their families. Boydell et al. (2009) call on researchers to include such views in future explorations of the practices involved in healthcare integration, a call to which I respond in this study.

### **Studying Interagency Collaboration through Informational Continuity**

Despite the large volume of work on interprofessional collaboration, little consensus exists regarding the terms used to denote the kinds of collaboration involved. As previously mentioned, studies in the field refer both to professionals from different backgrounds working in the same organization and to professionals from similar backgrounds, but in different organizations, working together. To bring clarity to the discussion, and as a contrast to hospital-community collaboration, I refer to collaboration in which professionals from different backgrounds work together within the same organization as co-located collaboration. This type

of collaboration has gained support as the preferred way of delivering services, as validated by the “gold standard” for evaluating medical interventions, randomized controlled trials (RCTs). Authors using RCTs report robust findings indicating co-located collaborative care improves functioning and increases family satisfaction in the treatment of adolescent depression (Richardson et al., 2009; Richardson et al., 2014) and disruptive behaviour disorders (Kolko, Campo, Kilbourne, & Kelleher, 2012).

Interagency collaboration consists of providers from different organizations working together in the service of a client or client system (Pfeiffer & Cundari, 2000). In Chapter I, I described the evolution of mental health services in River City as moving towards a system of care. This move draws from social policy initiatives originally developed in the early 1970s in the United States to coordinate care for adults with serious mental illnesses (Osher, 2002; Stroul & Blau, 2008). In relation to children, Goldman (1988) defined a system of care as: “a comprehensive spectrum of mental health and other necessary services, which are organized into a coordinated network to meet the multiple and changing needs of children and adolescents who are severely emotionally disturbed and their families” (p. 2). Boydell et al. (2009) refer to such systemic efforts (i.e., systems of care), whereby organizations combine services under a central hierarchy, as “vertical integration” (p. 15). Although efforts at vertical integration and creating a system of care are well underway in River City, the current service system is primarily horizontally integrated.

Due to the horizontal integration of the current system in River City, where care shared between agencies has recently received greater focus, continuity of care is a useful construct to describe service users’ experiences of interprofessional care. Continuity of care is an important concept in mental health services (Adair et al., 2003), but has not yet been addressed comprehensively in the counselling literature. Medical sociologist Leona Bachrach’s (1981) widely cited definition characterizes continuity of care as “a process involving the orderly, uninterrupted movement of [a] patient among the diverse elements of the service delivery system” (p. 1449). Haggerty et al. (2003) describe continuity of care as having two core elements: (a) care that an individual and/or family receives, and (b) how the client or client system experiences this care over time. This move toward person-centred care shifts the focus away from continuity of care as a measure of administrative procedures (i.e., from patient movements to patient experiences) and differentiates it from terms such as “continuum of care, coordination of care, discharge planning, case management integration of services, and seamless

care” (Haggerty et al., 2003, p. 1219). More recently, Tobon, Reid, and Goffin (2014) describe continuity of care as pertaining to both service users’ and service providers’ views on transitions, information sharing, and consistency of relationships between collaborating child and youth serving agencies. Their work follows that of a number of authors who, in their studies of young peoples’ and their families’ experiences of mental health care in Ontario, identify three dimensions of continuity of care: informational, relational, and managerial (cf. Haggerty et al., 2003; Waibel, Henao, Aller, Vargas, & Vázquez, 2012).

Tobon et al. (2014) define informational continuity as multiple providers using information about prior events and social context to tailor care directly to the individual service user. Relational continuity involves an ongoing therapeutic relationship between the service user and one or more service providers as they move between elements of the service system; different providers may be involved at different times and may range from the core team providing inpatient care to long-term care providers. Finally, management continuity refers to organizing timely and complementary services within a shared management plan as is sometimes described in relation to systems of care (Haggerty et al., 2003; Miller et al., 2009; Reid et al., 2002; Waibel et al., 2012). Researchers use these terms to demonstrate how families navigate mental health treatment systems, their experiences of consistency between workers, and how workers themselves integrate families’ views into treatment processes (Heller & Solomon, 2005; Tobon, Reid, & Brown, 2015).

### **Gaining Access and Moving through the System**

Authors of literature on access to and use of mental health care for young people and their families report that the ethnocultural background and socio economic status of both parents and youth is associated with greater difficulties accessing services and poorer treatment experiences. For example, Cummings, Ponce, and Mays (2010) demonstrate that in a national survey of mental health treatment access for youth in the United States, significantly fewer youth of Asian, African American, and Hispanic backgrounds accessed needed treatment for depression than similar youth of non-Hispanic White backgrounds. Researchers also describe parents of Hispanic and African American backgrounds experiencing greater difficulties with child welfare services than parents of non-Hispanic White backgrounds (Cheng & Lo, 2012). In regards to access to more specialized services, a lack of racial/ethnic differences in school-based service use has been documented when compared to significant racial/ethnic differences in clinic-based service use among youth who demonstrate high levels of need for mental health

services (Cummings, Ponce, & Mays, 2010). These findings complement evidence from large scale reviews that youth from Non-White ethnic backgrounds and with lower family incomes experience greater difficulties accessing and benefiting from specialized mental health services (Costello, Egger, & Angold, 2005; Kessler & Cleary, 1980).

To gain access to specialized mental health services as a part of interagency care, young people and their families must be identified as needing a variety of mental health services. A range of quantitative studies describes young people and their families' access to, and experiences within, mental health systems (Farmer, Burns, Phillips, Angold, & Costello, 2003; Offord, 1987). These studies highlight how young people generally first encounter support for mental health difficulties and their subsequent experiences within these mental health systems and provide a broad context for specific aspects of interagency collaboration and continuity of care. In general, large-scale studies on this topic rely on questionnaires that assess reports of both young people's psychiatric difficulties and their use of mental health and other psychosocial services. Seminal studies such as the Great Smoky Mountains Survey (Farmer et al., 2003) and the Ontario Child Health Study (Offord, 1987) show that young people often access psychosocial support services through the education sector, but that many young people who suffer from psychiatric difficulties do not access services at all. Authors of these studies report on the characteristics of large-scale mental health systems that contribute to families' overall experiences of interagency collaboration.

For example, Offord (1987), reporting on service usage data from an Ontario-wide survey, found that only 16.7% of children who met criteria for one or more psychiatric disorders in the six months preceding the survey used mental health or social services over that same time period, while approximately 58.7% of those children used ambulatory medical services (i.e., family doctors and emergency rooms), but were not connected to specialized mental health services. Davidson and Manion (1996), describing the needs of youth in Ontario, argue that Offord's (1987) results indicate that service providers, such as family physicians, are not well-equipped to identify and appropriately refer children and youth struggling with mental health difficulties. They further observe that youth do not often seek help from mental health services on their own initiative.

Farmer et al. (2003) report the results of a longitudinal study where researchers surveyed young people in a predominantly rural region of the southeastern United States (n= 1,420), annually over four years, regarding their psychiatric difficulties and service use. Through

illustrating chains of service use, Farmer et al. (2003) demonstrate that when young people entered services through the specialty mental health sector, they generally presented with more severe mental health difficulties, and were more likely to access additional services than youth who entered mental health services through the education sector—the most common entry point.

Large-scale studies by Offord et al. (1987) and Farmer et al. (2003) report on general trends in how young people come to, and move through, services. Their results are instructive in looking at how young people enter services and on their experiences between services; however, the studies provide less information about young people and their families' experiences of working with multiple agencies. Researchers who focus on families' use of services across sectors use surveys distributed to service providers to identify relationships between service sectors, as well as reviews of charts and administrative data that track service use (Pavkov, Soloski, & Deliberty, 2012). Small-scale studies use combinations of Likert-style questionnaires and open-ended questions to track service providers and families' descriptions of service use (Koren et al., 1997; G. J. Reid et al., 2011). These smaller scale studies demonstrated that families felt that they were lost between services, and that the severity of a child's difficulties, combined with the number of services used, often resulted in families expressing less satisfaction regarding the level of service coordination and the quality of their contacts with service providers (Koren et al., 1997; Pavkov, Soloski, & Deliberty, 2012; Reid et al., 2011).

Koren et al. (1997) wrote a pivotal paper that explored service coordination from the perspectives of parents whose children suffered from emotional difficulties in Multnomah County, Oregon. The authors used structured interviews and questionnaires to elicit views from 266 families whose children had been assigned a diagnosis, based on their struggles in at least two areas of their lives (e.g., school, relationships, home life), from the then-current revision of the second edition of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM-II-R). Koren et al. found that the more psychiatric symptoms children displayed, the less families rated services as coordinated. However, the authors did not report any relationship between the number of services involved and family ratings of coordination. The authors conclude that "parents tended to view their children's needs as comprehensively met to the extent that they were satisfied with individual services and viewed services as coordinated" (p. 170). Koren et al.'s (1997) work demonstrates the importance of high quality service delivery with a particular emphasis on coordination among services. These authors also show how service

providers' efforts at coordination being visible to families allows these service users to recognize services as coordinated.

Using both qualitative and quantitative measures, Pavkov, Soloski, and Deliberty (2012) conducted a wide ranging inquiry into how service providers and parents of service users in a statewide program, in the Midwestern United States, perceived their various roles based on their location in the service system—what the authors referred to as “the socially constructed realities of human service providers” (p. 672). Pavkov et al. (2012) distributed a survey using 28 Likert-style questions that the authors selected from a tool for assessing local mental health service systems (adapted to capture parent and service provider views on the needs of children and youth with serious emotional disturbances) (Morrissey, Johnsen, & Calloway, 1997). Pavkov et al. (2012) also included an open-ended question asking, “Are there any major obstacles or barriers that remain to be overcome in order for the mental health system and related services for children with serious emotional disturbance to be provided in a coordinated and comprehensive manner?” (p. 675-676). Surveys were completed by 1,428 persons, which included service providers from five areas: education ( $N=537$ ), justice ( $N=137$ ), child welfare ( $N=121$ ), private ( $N=420$ ), and community-based mental health care ( $N=96$ ). The study also included service users: 116 family members (parents or consumers). The authors identified patterns of “finger pointing” (p. 681) between different agencies (e.g., juvenile justice, education, mental health) that were located in different funding silos, which was reflective of differing realities between agencies and resulted in service providers “downplaying their own limitations while emphasizing them in other systems” (p. 685). They also identified that service users (i.e., children and their families) felt lost between the various systems.

To provide a closer view of how clients use children's mental health services, Reid et al. (2011) characterize how families sought out services by studying 300 families of youth struggling with mental health difficulties recruited from five Ontario-based service sectors (i.e., mental health, medical, education, child welfare, and juvenile justice) that were not vertically integrated into a System of Care. Through questionnaires and administrative data (i.e., chart reviews), the authors collected data on the services these families had used and traced the families' concerns. Reid et al. (2011) report that approximately 30% of families surveyed used medical, mental health, and educational services concurrently, and 65% of these families recalled seeking help from all three sectors for the same concern. The authors argue that their findings show a more complex pattern of service use (i.e., families accessing multiple services at the same

time) than had been previously assumed. Reid et al. (2011) recommend that agencies in related service sectors (e.g., education, youth justice, mental health) forge stronger connections with each other in order to reduce overlapping service use by families.

Overall, quantitative studies of young people and their families' experiences within mental health systems show that, beyond barriers faced by young people and families of diverse socio-economic backgrounds, many children and youth do not access needed services and the services they encounter are often disconnected (Davidson & Manion, 1996; Offord, 1987). Large-scale studies show youth with serious mental health difficulties are often not identified and connected with services in a timely fashion, and many young people and their families seeking mental health services may access many services at the same time (Pavkov et al., 2012; Reid et al., 2011). Previous studies show that families experience services as less coordinated as their children's difficulties become more complex, and that they may seek services from multiple agencies concurrently (Koren et al., 1997; Reid et al., 2011). To better describe these experiences, some authors have investigated client entry to, and use of, mental health services through qualitative and mixed methods studies. These measures have included chart reviews and semi-structured interviews. In general, authors found that families are concerned about wait times, achieving timely access to services, and consistency (Boydell et al., 2006; Raingruber, 2003).

For example, Boydell et al. (2006) conducted a large-scale, qualitative study of families' experiences of seeking mental health treatment for children and youth in two rural Ontario communities. The authors conducted semi-structured interviews with parents from 30 families regarding their experiences of the treatment of their children (aged 3-17 and formally diagnosed with an emotional and/or behavioural disorder). The investigators also held focus groups with community stakeholders and with both frontline and administrative staff. Boydell et al. (2006) describe the typical family journey to securing mental health care for their child as "complex, constantly changing and non-linear . . . more like a labyrinth or a tangled web than a pathway" (p. 187). The authors conclude that families experience tension between finding services by word-of-mouth in rural communities and feeling exposed when seeking services, an aspect of seeking mental health care that may be unique to rural communities. Boydell et al. (2006) also made several recommendations around early access, health promotion, and integration of services that may apply beyond rural communities.

Raingruber (2003) investigated the experience of 10 clients and 40 service providers regarding the recognition and treatment of depression and suicidal ideation within four counties in an American state. Raingruber (2003) conducted focus groups with service users and the majority of service providers (nurses, social workers, and police officers) except for a number of family physicians whom she interviewed individually due to scheduling difficulties. She asked all participants four questions about the experience and care of depression and suicidal ideation. Raingruber (2003), who used a phenomenological approach, identifies three themes, and she describes a paradigm case where a participant described how “mental health care is more like a big puzzle all broken apart, with individual pieces shuffling around in the box” (p. 154). In her thematic analysis, the author recounts participant descriptions of fragmented mental health systems as lacking in caring and personal interaction and describes reimbursement structures that contribute to the current state of affairs. She argues that mental health treatment systems need to prioritize personalized patient care and use reimbursement structures that support collaboration between inpatient and outpatient mental health services.

Boydell et al. (2006) and Raingruber (2003) demonstrate the difficulties clients experience in finding and engaging mental health services. They identified service users’ needs to have consistent staff and to be aware of how to access services, find additional supports, and maintain connections with their existing service providers. These studies identify factors, such as wait lists and disconnected services, that discourage young people and their families’ connections to services. Qualitative studies of client experiences of collaborative services add to quantitative findings on access and engagement. The results of these studies demonstrate how, when service users feel that their services are disconnected, they may follow patterns of seeking multiple services (Reid et al. 2011), or how disconnected service providers (Pavkov et al. 2013) may contribute to feelings of disjointed services described as a broken puzzle (Raingruber 2003) or a tangled web (Boydell et al. 2006). These disjointed services may be the result of large-scale disconnections between service systems in primary care (Davidson & Manion 1996; Offord 1987), and in chains of access to services (Famer et al., 2003). Taken together, the research literature reveals a common experience of disconnected services.

Both qualitative and quantitative studies reviewed above tell the story of young people and their families accessing mental health and psychosocial support services through channels including family doctors, schools, and directly through the mental health sector. This story includes many experiences of disconnected services both from the perspective of service users

and service providers. While the studies above provide descriptions of reasons behind these feelings of disconnection, they provide little to narrate the stories of individual families as they pursue mental health services shared between agencies. These studies, coming from locations both in the Canadian province where River City is based and in various locations in the United States, provide some general indications of the barriers that families may face. To further elucidate service users' experiences of services coordinated between agencies, authors have relied on these individuals' experiences of how service providers share information between agencies, as reviewed in the next section.

### **Consistency of Information**

Researchers have also studied specific instances of collaboration between service providers that demonstrate how families experience consistency in their relationships with different service providers. Authors of these qualitative studies generally followed young people and their families as they engaged in treatment and asked clients about their experiences of service providers working together (Cohen, Calderon, Salinas, SenGupta, & Reiter, 2012; O'Reilly et al., 2013). These authors identified numerous themes regarding family experiences of providers working across horizontally integrated agencies. They collected data regarding interagency collaboration through focus groups and individual semi-structured interviews. Both Cohen et al. (2012) and O'Reilly et al. (2013) present findings that show parents reported feeling that service providers were working together consistently in the interests of their children when parents were provided with adequate documentation and when service providers demonstrated familiarity with the family's concerns, so that the families did not have to repeat their stories multiple times.

For example, Cohen et al. (2012) conducted focus group and individual interviews with 25 families in a predominantly Hispanic area of California about their experiences accessing child and adolescent mental health services. The authors were interested in how and why families accessed services, family impressions of clinicians, and family experiences of working within the rules provided by both healthcare coverage providers and service providers as they engaged in treatment. Cohen et al. (2012) conducted a phenomenological analysis of family experiences of seeking care that guided their thematic analysis, which they later contextualized using service provider input. Results indicate that parents were frustrated when confronted by different treatment perspectives from different professionals or when they experienced long waits while being referred from one professional (e.g., their family doctor) to another (e.g., a

mental health professional). Cohen et al. (2012) identify specific administrative barriers, such as parents having to take their children to multiple assessments, and they stress the importance of the primary care physician ensuring that health plans make the pathways to mental health treatment clear to, and as easy as possible for, participating families.

O'Reilly et al. (2012) conducted in-depth interviews with 12 families of children under 12 (14 parents, 11 children) who received services from children's mental health (referred to as CAHMS) and education sectors in the United Kingdom. The authors conducted 25 semi-structured interviews, interviewing children and their parents separately. Interviewers used varied means of collecting data including allowing children to draw when appropriate. The authors performed a thematic analysis of the results related to the research question: "What are the perceptions and experiences of parents and children of joint working between CAHMS and education?" (p. 3). O'Reilly et al. (2012) report that parents felt that collaboration of service providers significantly improved their family lives. Parents and children reported feeling that collaboration, especially when it included educational services, had positively influenced teachers' behaviours towards the children. Parents said they noticed significant positive changes in their children's well-being, which they connected to service providers' collaborative efforts. At the same time, parents also described feeling that they had to navigate more services due to the involvement of multiple agencies, and they complained that they received inadequate documentation of their children's treatment (O'Reilly et al., 2012).

Authors of recent investigations of young people and their parents' experiences report that clients experience difficulties when their care is not consistent across services, and that children, youth, and their families grow increasingly frustrated when left to navigate multiple services on their own (Cohen et al., 2012; O'Reilly et al., 2012). Families appeared especially frustrated when they had to tell their stories multiple times and did not receive information regarding the next steps of their journey. These findings reinforce the need for consistent information sharing between service providers. The studies discussed above focus on how families experience professionals collaborating with each other; however, the dimension of informational continuity provides specific insight into client experiences of the consistency of information between service providers. Studies that describe client experiences of informational continuity show that young people and their parents described breaks in continuity of care that were most noticeable when clients felt that service providers' familiarity with their stories was

inadequate because the client information did not seem to travel from one service provider to another (Miller et al., 2009; Tobon et al., 2015; Waibel et al., 2012).

**Client experiences of informational continuity.** Waibel et al. (2012) reviewed 25 qualitative studies regarding the experiences of clients with diverse medical and mental health conditions, on three dimensions of continuity of care: informational, relational, and managerial. Waibel et al. (2012) review how respondents of each of these studies understood each dimension of continuity of care, the relevance they attributed to each, and respondents' understandings of the causes and consequences of lacks in any one dimension. The authors summarize that in regards to informational continuity, service users reported that receiving conflicting information from different service providers reduced their confidence in those providers and increased their anxiety about treatment. Waibel et al. (2013) also report that service users expected that their primary service provider have a holistic understanding, including not only their biomedical information, but also their values and preferences.

While drawing on a qualitative approach, Tobon et al. (2015) provide a closer examination of children and their families' experiences by using semi-structured interviews with parents of children 4-18 years of age (n=15), youth between 15-18 years of age (n=11), and service providers (n=10) regarding different aspects of continuity of care combined with demographic and administrative data regarding their backgrounds and service use. Using a thematic analysis, which they compare to existing dimensions of continuity of care, Tobon et al. (2015) demonstrate how families found it very important that service providers be aware of relevant treatment information. The authors report that parents tended to take on extra responsibility when they perceived that professionals did not adequately exchange information about their child's care.

In a deeper exploration of parents' views under very trying circumstances, Miller et al. (2009) conducted semi-structured interviews with the parents of 47 children with chronic conditions, including ADHD, and analyzed their findings using a framework approach that builds on the previously discussed dimensions of continuity of care. The authors describe parent statements about the significance of informational continuity indicating that written records augmented relationships in communication between workers, that this was apparent to parents, and enhanced positive parental experiences of service provision. Miller et al. (2009) argue that informational continuity was enhanced by parents' awareness of communication between service

providers, and cite various examples where parents were disappointed when they became aware of failures in communication between service providers.

Specific findings on client experiences of informational continuity complement studies on collaboration between service providers to reinforce the importance of consistent information. Combined, these studies demonstrate the importance that clients attributed to all of their service providers having similar information and using this information in a consistent manner. In addition, the studies reveal how clients became increasingly frustrated that they had to repeat their stories because their various service providers were not aware of previous work. .

The studies reviewed all capture retrospective views of clients, relying on young people and/or parents' recollections of continuity of care. Following a suggestion by Waibel et al. (2012), and with the exception of the work of Tobon et al. (2014,2015), the experiences of young people have been less well-studied than other populations regarding continuity of care in general and informational continuity in particular. In addition, a recent review of continuity of care literature by Naert, Roose, Rapp, and Vanderplasschen (2017) found that the majority of studies on continuity of care focus predominantly on management continuity and neglect the views of young people. Also, research by Tobon et al. (2015) combines the views of parents and young people and gives little information on young peoples' individual experiences of continuity or the evolution of both young people and their parents' experiences of continuity of care over time. Finally, these articles do not describe specific characteristics of the health systems within which research participants experienced.

### **Specific Service Provider Actions**

As described above, researchers report that services are well-coordinated when clients have clear access to consistent information. These findings provide guidance on ideal treatment relationships and ways that service providers share information. Researchers exploring interagency collaboration and continuity of care have also identified how service providers can facilitate these relationships. Studies of interagency collaboration have examined workers' efforts to include client perspectives and to consider them alongside the perspectives of service providers. Authors of these studies have used focus groups and thematic analyses of qualitative data to report on the specific ways that help clients feel that their perspectives have been integrated (Iachini, Hock,Thomas, & Clone, 2015; Widmark, Sandahl, Piuva, & Bergman, 2013).

For example, in a qualitative study from Sweden, Widmark et al. (2013) conducted semi-structured interviews with seven parents of children and adolescents who received interagency

treatment shared between service providers across child welfare and mental health agencies. The participants' children had previously received diagnoses of depression or anxiety. Through a content analysis of interview transcripts, Widmark et al. (2013) developed a tentative model where they sorted parents' perceptions of collaboration into categories of "the quality of contacts" or "the strength of collaboration" (p. 9). Their analysis reveals that parental perception that service providers were collaborating was related to the quality of contacts between parents and individual service providers. Parents reported that they felt relieved when they saw contacts between service providers as strong. In particular, parents cited being party to joint meetings between organizations that were "well-prepared and properly scheduled", to be reassuring (p. 7).

On the other hand, Widmark et al. (2013) report that meetings described by parents as being unsatisfactory or vague resulted in parents feeling less secure about their children's treatment. The authors report how these experiences emerged from family impressions that some of the professionals did not actually know their child and from parents having to repeat their stories. Widmark et al. (2013) also report that parents' feelings of trust in their service providers increased when providers' interactions were structured into what Widmark et al. (2013), following Petriglieri and Petriglieri (2010), call a "holding environment," characterized as "a social context that reduces disturbing affects and facilitates sense making" (p. 27). In this study, parents reported that being part of meetings where they felt that their child's perspective had been integrated was key to their feeling less anxious and to them being able to more easily understand service provider recommendations.

Although Widmark et al. (2013) present elements that support parents' positive experiences of interagency collaboration, Iachini, et al., (2015) focus on the perspectives of both parents and their adolescent children. Iachini et al.'s (2015) work is especially important given the previous review of literature on adolescent experiences of mental health treatment by Freaque, Barley, and Kent (2007), where the authors report a lack of specific guidance on how professionals can work most effectively with adolescents. Iachini et al. (2015) add an important dimension to the concept of collaborative care in their study of youth and parental perspectives on practitioner behaviours that promote treatment engagement.

These researchers identify a theme that they refer to as "collaborative service delivery," which they define as "provider behaviours that contribute to the collaborative delivery of services on behalf of youth and families served" (Iachini et al., 2015, p. 66). To arrive at this theme (among others), the authors used a thematic analysis of a semi-structured interview

conducted with one, one-parent focus group (n=11, 10 female) and two youth focus groups (n=19 youth, 7 females, 1 gender unreported). They report that one of their higher order themes is collaborative service delivery. In addition, of the subthemes identified, only “sharing treatment information” (its absence or presence) was mentioned by both youth focus groups and the parent group as important to their experiences. Parents also shared their preference for service providers to be culturally competent and to demonstrate awareness of other services and supports. Youth mentioned their preference for service providers to engage other adults whom young people considered important as part of their care, especially those who were not mental health professionals, such as teachers.

These studies of interagency collaboration provide guidance for practitioners by identifying actions of individual service providers that reinforce client feelings of satisfaction with how their providers share and use information. Recommending such actions builds on previous findings regarding consistency that also indicate that well-coordinated meetings and interactions between various service providers, which integrate client perspectives, demonstrate that service providers recognize and support parents’ efforts. In addition, appreciating service providers demonstrating awareness of other supports and adults in clients’ lives is a common theme raised by families across studies.

**Dimensions of continuity of care that reinforce informational continuity.** The literature also includes dimensions of relational and management continuity as distinctive parts of service users’ experiences of continuity of care (Heller & Solomon, 2005; Jones et al., 2009; Miller et al., 2009; Tobon et al., 2015). These dimensions relate to relationships with, and transitions between, service providers and are defined, following Tobon et al, (2015) as:

- relational continuity: a consistent relationship with one service provider or team over the course of treatment, and
- management continuity: organizing services in a timely fashion within a shared management plan.

Many studies looking at these dimensions of continuity of care emphasize the importance of on-going relationships so that young people and their families feel that their service providers know them as people, as opposed to simply *conditions* for which they are seeking treatment (Heller & Solomon, 2005; Jones et al., 2009; Miller et al., 2009; Tobon et al., 2015).

In contrast to their original exploration of an isolated notion of management continuity, Haggerty et al. (2013) report evidence that service users call for continuity to extend past the

three dimensions described above to include service provider awareness of how client conditions and proposed treatments (healthcare) connect to their life circumstances. Haggerty et al. (2013) conclude that a demonstrated awareness of the connections between healthcare and service users' lives lead to enhanced experiences of continuous care.

In a closer examination of client experiences of continuity of care, Jones et al. (2009) conducted semi-structured interviews with 31 adult service users from a broad range of ages (27-72 years of age), who struggled with severe mental illness, and 14 of their caregivers. These participants were selected from a larger study with particular attention to finding participants who had experienced the establishment of continuity of care between workers as particularly difficult (i.e., many professionals involved, many transitions between services). Jones et al. (2009) present an illness "career chart" (p. 637) that covers respondent encounters with mental health services, the services involved, respondent comments, and three themes related to relationships and transitions, according to respondents who:

- Stressed the importance of a relationship with one key worker, and who described losing this key worker as devastating;
- Described their disappointment with services being mostly reactive in nature; and,
- Identified transitions without adequate, timely information, and who described a lack of effective communication between service providers as being particularly difficult.

Jones et al. (2009) also report that caregivers in their study often felt excluded from their charge's mental health care. Jones et al. (2009) conclude that service users' feelings that their services are continuous are fragile, and this fragility relates to long-term mental health service relationships being easily undermined by sudden transitions implemented without adequate notice or information.

In a compelling exploration of extremely difficult experiences of healthcare services, Heller and Solomon (2005) conducted interviews with parents who had recently experienced the death of their child (n=36) at one of three teaching hospitals in the United States. Heller and Solomon (2005) report that respondents described themselves as much more trusting of healthcare staff when they experienced consistency in their relationships with them, in the information they received, and in transitions between services. Conversely when they perceived that relationships, information, and/or transitions were inconsistent, these parent research respondents described themselves becoming less trusting and, consequently, overinvolved in

their children's care. This appeared to follow from a parental perception that their healthcare providers did not know their child, which was based on an absence of informational and relational continuity.

The findings of Heller and Solomon (2005) on continuity of care are similar to those of Tobon et al. (2015) in the study I described above, that categorize the thoughts of parents, young people, and their service providers into categories of relational and managerial continuity, as well as informational continuity. In regards to relational continuity, Tobon et al. (2015) report that young people and their parents cited not having to repeat their stories as an important component in establishing trusting relationships with their service providers. Parents, service providers, and youth all emphasized the importance of the therapeutic relationship and connections between families and service providers. Families emphasized the importance of consistent feelings of connection with service providers in building trust that supported their continuous use of those service providers. Service providers described a delicate line between mandatory reporting (e.g., abuse, harm concerns) and maintaining relationships with the families. In addition, both families and service providers emphasized the importance of flexibility regarding scheduling availability in maintaining relationships. Finally, service providers and families emphasized the importance of carefully planning transitions between services because of the peril that sudden transitions often present for relationships.

In regards to managerial continuity, Tobon et al. (2015) report how young people, parents, and service providers spoke about believing that family members should be included in care, and how the inclusion of different parties related to consistent care planning. Youth respondents had different opinions on the degree to which they wanted their parents involved in their treatment, whereas parents talked about the importance of being included in seamless case management and service coordination to avoid the feeling that service was fragmented and that their family was not receiving adequate care. Tobon et al.'s (2015) findings reinforce the interconnectedness of relational, management, and informational continuity when clients and their service providers have been asked about their experiences of mental health systems. The findings of Tobon et al. (2015), when combined with previous studies, reveal how clients experience interagency relationships and, importantly, how these relationships influence experiences of consistency of information and feelings of connection with individual service providers through demonstrated knowledge of a client's stories and individual desires for treatment (Haggerty et al., 2013; Heller & Solomon, 2005; Jones et al., 2009).

Studies that investigate client experiences of management and relational continuity show that consistent and predictable relationships between clients and their service providers reinforce familial feelings that these relationships are secure (Haggerty et al., 2013; Jones et al., 2009; Tobon et al., 2015). Clients expect to have control over who is involved in their care, but parents and other caregivers often feel excluded from their charges' care journeys (Tobon et al., 2015; Jones et al., 2009). Clients also report wanting to feel that their treatment is integrated into their broader lives and that they are known by their service providers (Haggerty et al., 2013; Heller & Solomon, 2005). Researchers studying clients' experiences of continuity of care often use focus groups and individual interviews to capture both client and their service provider perspectives. Innovative approaches, such as describing *illness careers* (Jones et al., 2009), allow service providers to understand the longitudinal aspects of clients' journeys. Taken together, these research studies speak to multiple dimensions of client and families' experiences of the mental health care system.

### **Studying Collaboration and Continuity of Care**

The integration of mental health services for young people is a large undertaking. As this integration moves forward, service providers from different agencies endeavour to serve families within a yet-to-be-organized structure. As I described earlier, although efforts are well underway to organize these services in River City, a large proportion of young people and their families do not currently receive treatment within formal systems of care, so service providers must collaborate across agencies. Quantitative, large-scale studies of young people and their families' access to and use of mental health services show that services are often difficult to access and poorly coordinated (Farmer et al., 2003; Offord et al., 1986). These studies reflect similar trends to those occurring in River City. Previous studies on interagency collaboration describe families seeking similar services from different agencies at the same time (Reid et al., 2011), agencies working in "silos" (Pavkov et al., 2012), and the possibility of duplication of services. Studies of young people and their families' individual experiences of interagency collaborations demonstrate that families appreciated when services were coordinated and well organized (Koren et al., 1997; Tobon et al., 2015). Not only have past studies of interagency collaboration been vital for making explicit the experience of services users, they also provide evidence that service providers can use to improve support for clients and their families.

**Methodological considerations.** Existing research on client experiences of interagency collaboration focuses on how young people and their families access services, and the effects of

specific service provider actions on young people and their families' experience of connected services. Authors studying service providers' efforts at ensuring informational continuity have identified specific service providers' actions that improve client and family experiences of interagency collaborative care. However, while the literature highlights service provider actions associated with informational continuity, authors who study interagency collaboration through informational continuity fall short in depicting two aspects of service user experiences of interagency collaboration:

- the evolution of service user experiences over time, and
- the contexts in which these experiences evolve.

In regards to the evolution of service user experiences of interagency collaboration, depicted through informational continuity over time, authors of existing studies tend to report a snapshot of that experience based on a single interview. These snapshots, composed of retrospective interviews (Heller & Solomon, 2005; Jones et al., 2009; Miller et al., 2009) or retrospective interviews combined with chart reviews (Tobon, Reid, & Brown, 2015) fail to capture changes to client experiences over time. These snapshots are problematic because the current definition of informational continuity in mental health care involves client experiences of information sharing over time (Reid, Haggerty, & McKendry, 2002; Tobon et al., 2015). Therefore, existing studies of informational continuity and specific service provider actions fail to capture the evolution of families' experience following their entry into collaborative treatment. The needs of young people and their families change over time, therefore an action that may increase initial treatment engagement may later prove to be superfluous or harmful. It is therefore important to study how families' experiences evolve over time.

In addition, authors of existing research on interagency collaboration and continuity of care do not report on the contexts in which clients seek out and service providers deliver interagency collaborative treatment from these actors' perspectives. Existing research typically includes the background in which the results were collected and demographic characteristics of research participants. However, current research falls short of a call originally made more than twenty years ago by D. White (1992) in her critique of continuity of care research, that these studies should depict service users' responses to their context (natural milieu) and how treatment supports these service user responses. Reinforcing White's (1992) argument, authors of current social policy initiatives and critiques of current research call for increased attention to research

and practice that depict the experiences of service, centered on the experience of clients and their families (Boydell, Bullock, & Goering, 2009; Gagné, 2005; Kutcher & McLuckie, 2010).

In reviewing the current literature on interagency collaboration and continuity of care and responding to the need for studies that depict client perspectives, I have determined that it is important to understand and more deeply investigate young people and their families' experiences of collaborative care in River City. In particular, it is important to understand young people and their families' experiences of interagency collaboration, and the evolution of these perspectives over time, in the context of families' expectations of and service providers' perspectives on the delivery of interagency collaborative care. I investigate these experiences and perspectives through the following research questions:

1. How do families experience collaborative care in their interactions with various professionals (e.g., school, community, medical practitioners) regarding their child's psychiatric diagnosis? In particular:
  - a) How do young people and their families who are veterans of interagency collaborative mental health treatment describe their previous experiences?
  - b) How do new-to-treatment families describe their evolving experiences of continuity of care, specifically informational continuity, between the various professionals who collaborate to provide mental health care for their child(ren)?
2. What perspectives on collaborative care do community and medical professionals offer in response to this study's descriptions of new-to-treatment and veteran adolescent and family experiences?

### CHAPTER III: CONCEPTUAL FRAMEWORK

In River City, a recent and significant shift towards mental health service integration has brought many professional groups together with the expectation that they will collaborate to serve young people and their families who have been affected by serious mental illnesses. As I demonstrated in Chapter II, researchers have conducted numerous qualitative explorations into client experiences of interagency collaboration and continuity of care in children's mental health services; however, authors writing about these concepts have rarely acknowledged that service providers inhabit different professional cultures that influence their collaboration. As a result, few authors have considered how moving between professional cultures may affect families' experiences of collaboration. In my research, I focus on young people and their families' experiences of continuity of care between different groups of collaborating health care professionals who operate within specific community- and hospital-based contexts that I refer to as professional cultures. I conduct my investigation from a social constructionist perspective. Broadly speaking, in the social constructionist view, knowledge is contingent, created, and re-created among people, rather than a collection of eternal "truths" waiting to be discovered (Paré, 1995). Processes of communal knowledge construction take place within groups of people (e.g., ethnic, religious, linguistic) or within local communities (e.g., workplaces, shared professional backgrounds). I use a social constructionist lens to focus on families' experiences of mental health treatment received from different professional cultures. This approach builds upon previous research where authors demonstrate that community based service providers such as counsellors are unfamiliar with medical models and argue for an increased focus on interprofessional education for counsellors and medical professionals (Arthur & Russell-Mayhew, 2010; Kipick Cawn, 2014; Lee, Schneider, Bellefontaine, Davidson, & Robertson, 2012).

The concept of professional cultures itself is based on social constructionist assumptions and is key to this investigation. In this chapter, I first describe how I will characterize experience from a social constructionist orientation and how this characterization differs from a traditional phenomenological approach. I then detail my view of professional cultures, which follows from the social constructionist perspective on knowledge as communally constructed. I conclude the chapter by describing how I apply this epistemological stance to my research by describing the assumptions guiding the present investigation.

### **Characterizing Experience**

Given that my investigation concerns experience, it is necessary to differentiate the social constructionist understanding of experience from other epistemological approaches. Researchers using a traditional understanding of experience base their work on epistemological traditions such as post-positivism where they aspire to observe phenomena from a detached and objective position, following a pre-defined set of steps and procedures (Creswell, 2007).

### **Social Constructionism**

The social constructionist position represents a significant shift in perspective from the traditional social science or positivist perspective. This postmodern perspective critiqued the notion that such a neat separation between event, context, and observer is possible (e.g., Haene, 2010). From a social constructionist perspective, the social, environmental, and historical contexts of the investigation, as well as the effects of the context on both researchers and research participants, are all relevant to the meanings ascribed to the event (Schwandt, 2000). In other words, social constructionist scholars and researchers reject the possibility that there is a direct, one-to-one relationship between the world and the words used to describe the world. Instead they work to highlight the ways that language, like all knowledge, is communally held and, therefore, inevitably reflect the shifting quality of its context or community. Therefore, in the present study, I examine how young people and their families describe their treatment experiences. I contextualize these experiences within my own knowledge and experience of the field to demonstrate how families' descriptions have been influenced by shifts in approaches to service provision, giving the readers a sense of the communal influences on my interpretation of these families' experiences.

This approach differs markedly both from transcendental phenomenological consideration of experience and the epistemological perspective of social constructivism. In regards to a traditional investigation of experience, the practice of transcendental phenomenology fits with a post-positivist epistemological position where researchers understand themselves to be separate from the data they collect (Moustakas, 1994). According to Husserl (1977), who was followed by Giorgi and Giorgi (2003), a transcendental phenomenological understanding of experience consists of reducing descriptions of an experience by a particular participant to the essence of the phenomenon under investigation. Giorgi and Giorgi (2003) provided the example of a cup, which may be reduced to the following essence: "[a] container of liquids manageable by hands" (p. 247). Transcendental phenomenologists liken the reduction of

a cup to its essential characteristics to the study of an experience where investigators are able to put aside their previous experiences of the world through “bracketing” (Creswell, 2007, p. 59), which allows them “to take a fresh perspective toward the phenomenon under investigation” (pp. 59-60). This approach would not be appropriate for my study given that I was both a researcher and a participant in the field that I investigated (i.e., collaborative mental health care for children and adolescents). Therefore, I could not “bracket out” my previous experiences because I continue to have, construct, and re-construct my own experiences in the field of collaborative mental health care. In other words, I chose to approach the field of collaborative mental health care for children and youth as the metaphorical water in which both participants in my research and I were swimming fish. This approach precluded my taking a neutral stance towards research participants’ experience. Acknowledging that I was not neutral in this investigation fits broadly with a social constructionist approach to the research topic. This approach, following Paré (1996), subsumes a social constructivist approach—where the researcher describes research participants constructing reality—by considering how both participants in my research and I co-constructed the experiences that I later wrote about.

**Application of a Social Constructionist position.** To put this epistemological stance into practice I relied on a hermeneutic phenomenological approach informed by a social constructionist orientation. In conducting my investigation from a this approach I dispensed with the notion that the investigator exists outside of the research process and can take a “fresh perspective” on the essence of the phenomenon being explored (Strong & Locke, 2010). Instead, following a social constructionist orientation toward experience I considered research participant’s accounts of their experiences (e.g., in the interviews I conducted) to be co-constructed by these participants and me as the interviewer. By co-construction I mean that the data generated from interviews are based on the experiences research participants described and the questions I asked about their experience (McNamee & Gergen, 1992). In my dissertation, I emphasize this co-construction by illuminating the contexts (i.e., professional cultures) where these experiences take place. In addition, the context of this study includes my experiences of these professional cultures through my work in and engagement with the Children’s Hospital and the Community Agency. Paying attention to context fits with a hermeneutic view of research where investigators understand the description of a phenomenon to be inextricably linked to an investigator’s perspective (Laverty, 2003; van Manen, 1997). I use this focus on the investigator’s perspective as also shaping the description to illuminate my co-construction of the

research data with research participants. The consideration of co-constructed meaning implies that I am not merely collecting data during an interview, but working with the research participants to put together an account of the phenomenon under investigation, mediating between their descriptions and my understandings of their descriptions (Haene, 2010). To apply this perspective, I relied on the concepts of discourse and professional cultures, which inform the assumptions I bring to this research that I describe later in this chapter.

**Discourse.** Social constructionist researchers and scholars have used the term *discourse* (Foucault, 1984) to describe the social, environmental, and historical contexts that influence what people hold to be true, and how they, therefore, describe the world. Tannen (1989) describes discourse as a “language beyond the sentence” (p. 6) that underlies the words we say and determines the ways that people communicate with others from a similar culture. Discourses are patterns of belief and related practice that are embedded in cultural and historical contexts (Monk, Winslade, & Sinclair, 2008; Potter, 2007). Studies of discourse have investigated how people use language and how their descriptions of the objects and ideas around them change based on their mutual contexts (Clarke, 2005; Lock & Strong, 2010). Through its focus on discourse, social constructionist theory has shed new light on language, and language use, moving away from the notion of a direct one-to-one relationship between words and the world and, instead, focusing on why particular descriptions hold sway among particular people in a particular time and place.

A focus on discourse enables scholars and researchers to understand their accounts of participants’ experiences as only one of many accounts available to describe such events. Furthermore, from a social constructionist perspective, the descriptions shared by people within a given society also exist among many possible accounts of or positions on particular events (Denzin, 2009; Lerner, 2003; D. E. Smith, 1978). Social constructionist scholars and researchers argue that discourse affects all persons within a cultural group, and that certain discourses within any group are privileged (Burr, 2003; Gergen & McNamee, 2000). Therefore, scholars seek to illuminate the effects of these privileged discourses or unspoken rules on everyday thoughts and actions. One method of understanding discourse involves studying the assumptions, stories, and words presented by different groups contained within a larger society. From a social constructionist perspective, people—including scholars and researchers—are always speaking from different cultural locations, or sub-cultures, which are influenced by discourses. These discourses underlie the definitions various service providers use and the practices they

implement as a result of these definitions; a shared discourse defines service providers as part of a particular professional culture.

### **Professional Cultures**

The “sensitizing concept” (Blumer, 1954), professional cultures, informs my investigation into the experiences of young people and their families who received horizontally integrated treatment from professionals working at both the Community Agency and the Children’s Hospital, whom I argue constitute unique sub-groups of professionals with shared discourses discrete to each sub-group. In using the metaphor of cultures to describe sub-groups, I am careful to note that all members of a society are differently engaged in many cultures that, together, constitute the unique meaning-making contexts from which any participant speaks and acts. Social constructionist theorists, therefore, speak of knowledge as situated (Haraway, 1988) in a speaker’s personal and professional cultural sub-groups (e.g., socio-economic status, profession).

As Hall (2005) describes, collections of professionals who share the same training constitute professional cultures that develop their own terminology and definitions. Hall’s (2005) understanding of professional cultures comes out of the literature that characterizes interprofessional collaboration. Further, in studying how groups of professionals interact, researchers in the field of interdisciplinary studies argue that professions are recognizable not only in their definitions, but also in how these professions relate to other professions (B. Davis & Sumara, 1997; Klein, 1996). Some interdisciplinary scholars, such as Stanley (2006), claim that the roles of professions, and indeed institutions, are best understood in relation to other professions and institutions.

The understanding of professions in interdisciplinary studies has evolved from Petrie’s (1976) descriptions of professions through cognitive maps of professional territories to more recent scholarship by Hall (2005) that provides tools to understand professions as cultures. Building on Petrie’s (1976) cognitive maps, the notion of cultures implies a shared repertoire of definitions and connected practices resulting from shared historical legacies, and drawing from a social constructionist understanding that cultures are made up of groups of people who share discourses. In other words, members of cultural sub-groups follow largely unspoken rules regarding what is acceptable within a given profession and how members of one professional group relate to members of another professional group.

Hall (2005) provides a description of the development of such cultural rules by reviewing the histories of professions such as medicine, nursing, and social work to demonstrate how professional cultures can act as barriers to interprofessional communication, because they use different descriptions of both problems and solutions. Hall (2005) argues that professions such as social work and medicine have their own particular ways of speaking and acting, and consequently use different words and practices to conceptualize the problems of their clients, which hinders communications between professionals. As Hall (2005), following Schroeder, Morrison, Cavanaugh, West, and Montgomery (1999), claims: “Each health care profession has a different culture, including values, beliefs, attitudes, customs and behaviours. This culture is passed on to the neophytes in the profession, but it remains obscure to other professions” (p. 188). Hall’s (2005) definition of professional cultures makes claims similar to the work of scholars in transcultural psychiatry whose work is epitomized by Arthur Kleinman’s (1978) characterization of the medical profession as a unique cultural system analogous to “kinship and religious systems, symbolic systems built out of meanings, behavioural norms, and the like” (p. 86).<sup>7</sup>

My use of the concept of professional cultures relates to qualitative descriptions of practices shared by members of the Children’s Hospital and the Community Agency, based on their shared work and the historical legacies that I describe further in Chapters III and V. I therefore investigate research participants’ experiences of two professional cultures in interaction with each other in the context of interagency collaboration. Following from a social constructionist understanding of professional cultures, the assumptions I discuss next guide my investigation into families’ experiences of collaborative care provided by the Community Agency and the Children’s Hospital.

---

<sup>7</sup> Hall’s (2005) and Kleinman’s (1978) views of professional cultures regarding shared practices and beliefs differ from the study of the concepts *organizational culture* and *organizational climate*. These concepts both refer to norms and shared perceptions within a specific organization and are assessed through quantitative measures (Glisson, 2002; Wolf, Dulmus, Maguin, & Cristalli, 2014).

### **Assumptions that Guide this Investigation**

From a social constructionist position, the construction of knowledge involves people working together to understand and construct meaning about the world in particular times and places. This collective work involves discourses about the “reality” of the world in these particular times and places. More specifically, what people do and say in a given interaction is influenced by discourse, and reflects the meanings attributed by the participants. In turn, the discourses influencing what people do and say reflect the time and place (i.e., the particular historical era and the physical location) in which they are created, interpreted, and subsequently put into action, all of which may differ from each other. As a consequence, the words that people share inescapably reflect the cultural context in which those words are imbedded. In this study, I am particularly interested in professional cultural contexts. These contexts consist of different practices and beliefs shared by service providers who work in either the Children’s Hospital or the Community Agency.

In my inquiry into the experiences of families about these two organizations that operate within River City’s children’s mental health system, and following from a social constructionist understanding of professional cultures, I assume that *social practices* enacted by members of a particular cultural group serve to sustain what is considered knowledge in that particular group (Burr, 2003; Gergen, 1985; Lock & Strong, 2010). Such social practices unfold from the discourses that members of each particular cultural group share.

I define discourse, following Burr (2003), as “a set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of events” (p. 64) and that are used within a particular sub-culture, such as the professional cultures I described above. Discourses reflect accepted beliefs regarding health, illness, and what is possible, or impossible, in a given time and place (Leonard, 1996); discourses guide the social practices put into place by their respective professional cultural groups.

In this investigation, I explored young people and their parents’ descriptions of how service providers from two distinct professional cultures understood and responded to the problematic thoughts and behaviours for which these young people received psychiatric diagnoses and mental health treatment. In particular, I studied how young people and their parents described the practices of their treatment providers following a psychiatric diagnosis. In line with a social constructionist orientation, I assumed that the ascription of, and treatment

following from, a particular psychiatric diagnosis is based upon the context (i.e., the professional culture) where the diagnosis was created and assigned. These psychiatric discourses follow from contrasting educational curricula of medical (Wear, 2004) and community-based knowledge, I make explicit in this dissertation.

A specific example of these community and medical curricula are the differing labels of “patient” and “client” that are often used interchangeably when referring to the users of mental health services. Shevell (2009) demonstrates that the word *patient* implies a passive role which removes responsibility from the service user. Further, commenters from medicine, psychology, and social work argue that the word patient is a relic of a paternalistic model of health care where this care is imposed upon those who are referred to as patients (Chamberlin, 2005; Shevell, 2009; Simmons, Hawley, Gale, & Sivakumaran, 2010). In comparison, the word *client* resulted from a humanistic movement in psychology to refer to recipients of services in more empowering terms (Shevell, 2009). However the etymology of the word *client* also implies someone who is dependant on others. Various authors have also demonstrated that the word client has origins in a neo-liberal conception of social services as goods distributed to “deserving” recipients of services (McLaughlin, 2009; Reaume, 2002; Shevell, 2009). Moreover, contemporary social work scholars argue for the use of the terms “service user” as an evolution from the term “consumer” to imply a relationship between provider and those who use services that is not a one-way hierarchical relationship between a helper and a person who is receiving help (Hübner, 2014; McLaughlin, 2009)<sup>8</sup>. However, the terms *client* and *patient* remain ubiquitous in the psychiatric and counselling literature and in the field of mental health care in River City. Indeed, in the course of my work in different organizations I have become keenly aware of the use of the terms client and patient in the different contexts in which I work.

To reinforce my observation that these terms are ubiquitous, a recent review by Dickens and Picchioni (2012) provides a further example of the practice of assigning labels that are particular to specific contexts, showing a possible effect of differing curricula on service users. In this review, the authors summarize studies involving 3,557 adult mental health service users who were asked if they preferred to be referred to as “patients” or “clients.” The researchers report that respondents expressed their preference to be referred to as “patients” by psychiatrists and as “clients” by community mental health professionals (Dickens & Picchioni, 2012). The

preferences expressed by these service users lend support to the idea that particular professional cultures use specific labels, which follows both Hall (2005) and Kleinman's (1978) descriptions of cultures as being organized around specific assumptions. In this dissertation, the cultures represent certain meaning-making contexts.

To further demonstrate context-based social practices that are embedded in the unique curricula and culture of various settings, I borrow an example from Kirmayer and Young (1999) who write, "Monks who take a vow of silence differ from children with selective mutism not in the internal functioning of mechanisms, but in their reasons for refusing to speak in the social context that engenders such mutism" (p. 450). In other words, a child who does not speak in certain contexts would be described differently (i.e., as being fearful of adults) than a monk who has vowed not to speak (i.e., as having religious devotion). Although in certain situations these actions may have similar consequences (i.e., being unable to ask for what one wants), it is also likely that others' reactions to a monastic monk would be different than their reaction to a selectively mute child. As Kirmayer and Young (1999) argue, these reactions had little to do with the individual causes of these children and monks not speaking and more to do with each respective population's responses to their social context.

In both of these examples, the ways that people are either defined or prefer to be defined by others, are based within particular groups. Social constructionist theorists understand these groups to be made up of people whose life circumstances (e.g., work, concerns about specific problems) are guided by particular discourses. In the case of mental health service users, the terms "patient" and "client" carry different expectations for how service providers will respond. For instance, "patient" is a term that has traditionally implied a more passive role for the service user (Chamberlin, 2005). In the example of mutism, the particular context of a person who exhibits a particular behaviour (i.e., refusing to talk) determines the ways that this person is defined and the particular practices that this person is subject to (i.e., mental health treatment versus the giving of alms). In the following section, I describe how practices mobilized in response to particular definitions serve to maintain these definitions.

### **Resultant Social Practices**

Each discourse, and therefore each professional culture, contains its own related and distinct social practices. Following from the preceding descriptions of discourses and

---

<sup>8</sup> The notion of receiving help and that of dependency have also been the subject of critical inquiries. For a helpful

professional cultures, I consider specific *social practices* to be actions specific to the respective professional cultures of the Children's Hospital and the Community Agency. In my exploration of these social practices, I investigate the different practices put in place by health and social service professionals, following examples that come out of these various professional cultures' existing literature.

For instance, Madsen (2014) provides a salient example of social practices that differ between professional cultures when he presents parallel trends between the evolution of family-centred services and the medicalization of mental health difficulties. Madsen (2014) writes about trends in the United States where the systems of care I described in Chapter II have increasingly integrated service providers, whose practices involve working with young people and their families in their homes and communities, into pre-existing mental health treatment systems. These treatment systems traditionally involved office-based work or psychotherapy services that took place in private offices and used medicalized definitions to guide their practices. Madsen (2014) refers to the agencies where service providers went to families' homes as "family centred services" (p. 2). Madsen and Gillespie (2014) contrast the social practices of community practitioners with office based practitioners in the following way:

The work [of community practitioners] is not about sitting and talking with people to work through their issues but walking and talking alongside them in ways that open up opportunities for them to experience themselves differently and change their life stories. (p. 9)

In an earlier work, Madsen (2009) illustrates how the practices used by service providers in offices (which followed from medicalized descriptions) and the practices used by workers who met families in their homes and communities were portrayed differently through conference and educational materials. He describes how medicalized practices developed in laboratories were often promoted as ideal ways of working. Madsen (2009) compares the promotion of these medicalized practices with the everyday practices of walking and talking practitioners, which were not as well researched. In his more recent work, Madsen (2014) points out additional distinctions in remuneration and status between office- and community-based service providers: "[the distinction between walking and talking and sitting and talking] reflects the class system of health and human services which elevates the efforts of some and obscures the good work of

others” (p. 13). This “class system” described by Madsen (2014) is one manifestation of discourses that determine whose knowledge takes precedence and the different statuses ascribed to hospital- and community-based service providers.

In mental health systems, a medical discourse that describes difficulties as located within the individual is currently the predominant language. This language is privileged over models that describe the difficulties as located within the individual’s contexts, which predominate in cultures of community-based service providers (Wampold, 2013). The predominance of the medical models reinforces hierarchies whereby practitioners such as clinical psychologists and physicians, who have the power to assign definitions (i.e., diagnoses) to particular problems, are granted greater power within mental health treatment systems. In my investigation, I elicited families’ descriptions of their experiences of care that was shared between service providers at the Community Agency, who cannot make psychiatric diagnoses, with service providers at the Children’s Hospital, where diagnoses are an integral part of the treatment protocols. In Chapter V, I describe these agencies in greater detail and pay specific attention to the ways that service providers carry out their work (their social/professional practices) and to families’ descriptions of their respective efforts.

In summary, my investigation of the stories of clients of the Ontario children's mental health system is based on assumptions that follow the social constructionist view that particular social practices create and maintain different bodies of knowledge that are informed by discourses shared by members of different professional cultures. I explore these social practices based on families’ descriptions, which I examine through the constructs of interagency collaboration and continuity of care. To further illustrate the professional cultures that underlay these social practices, I include my own reflections on my interactions with the Children’s Hospital and the Community Agency, which provide further context to families’ descriptions. In Chapter IV, I describe my methodological approach, to interpreting interagency collaboration and continuity of care in the context of professional cultures, which in turn contextualizes my investigation of the experiences that the research families and service providers recounted to me.

## **Moving Forward**

Based on the concepts and assumptions above, I depict interagency collaboration as it is described by research participants, with particular attention to the contexts that consist of clinicians’ professional cultures within River City’s community- and hospital-based children’s

mental health services. I integrate research participants' descriptions of their experience with the context where these descriptions were elicited following van Manen's (1997) hermeneutic phenomenology as my chosen research methodology. As I describe above, hermeneutic phenomenology follows from an understanding of experience as contingent on the context in which this experience is described. To depict the context of this particular study, I follow my conceptual framework and assume that, although clinicians from the Community Agency and the Children's Hospital share a focus on a particular population (i.e., young people with mental health difficulties and their families), the social practices they deploy in response to specific difficulties will likely be different. I attend to those differences through asking specific questions of research participants regarding their experiences within and between each professional cultural group and eliciting further feedback on my results from members of these groups. My social constructionist perspective argues that these different social practices are likely because they are a typical result of different unspoken rules or discourses that groups of similar professionals would have if they belonged to different professional cultures. Therefore, although I portray families' experiences of the actions of service providers who belong to different professional cultures through the families' descriptions of the social practices as they encountered them, I am not attempting to define the essential characteristics of how families experience specific professional cultures. Instead, I portray what families say about their experiences as reflecting the contexts they inhabit as well as my own influence in interacting with them. I understand these interactions with attention to the influence of professional cultures on specific encounters, which I reflect upon further in Chapter V.

In describing my methodology in the next chapter, I demonstrate the synthesis of a social constructionist focus on experience in the context of professional cultures to analyse data using the constructs of interagency collaboration and continuity of care. This synthesis informs both the tools I deployed to collect my data and my later analysis.

## CHAPTER IV: METHODOLOGY AND METHODS

In this investigation, I explore young people and their families' experiences of interagency collaboration, their descriptions of continuity of care, and service providers' reactions to summaries of these descriptions in River City. I use a social constructionist epistemological framework to investigate client experiences of interagency collaborative care for a young person's mental health difficulties. This epistemological framework involves a consideration of the influences of professional cultures on the social practices that research participants described.

As detailed above, I consider social practices described by research respondents to be the result of the multiple discourses that inform the respective professional cultures of the Community Agency and the Children's Hospital. To enhance my examination of these social practices, I have included my own experiences of the two professional cultures as well as reporting on research participants' experiences. My experience involved my work as a service provider and my additional contact with the agencies under investigation during the ethics approval process for this dissertation. Research participants' contributions involved three different perspectives on these cultures: (a) initial explorations of the experiences of adolescent veterans of collaborative care and their families; (b) the descriptions, as elicited by my questions about continuity of care, of adolescents and their families who were receiving collaborative care for the first time at the beginning and end of a three month period; and (c) reflections of service providers regarding exploratory maps that described my initial analysis of (a) and (b).

### **Methodology: Hermeneutic Phenomenology**

I investigated young people and their families' experiences of collaborative care in River City through an interview-based study guided by hermeneutic phenomenology (van Manen, 1997). Drawing on Donna Haraway's (1988) seminal work on "situated knowledges," I used hermeneutic phenomenology to illustrate the contexts of both the data I collected and the locations within which I observed the data. These contexts include spaces, such as the physical environments of the Children's Hospital and the Community Agency, and also discourses—unspoken rules that guide practices shared by particular groups of people.

To interpret my findings while keeping these contextual influences in mind, I relied on hermeneutic phenomenology. This research methodology involves considering a lived experience (phenomenology) holistically as it relates to the time and place the experience was observed (hermeneutics) (Creswell, 2007). Hermeneutics was used, originally, to interpret

biblical texts in light of when and where the texts were produced, and it subsequently evolved into a consideration of the context of a text's production and interpretation (J. A. Smith, Flowers, & Larkin, 2009). Following from the work of Heidegger (1967), hermeneutic phenomenology also involves the consideration of what influences an investigator's interpretations of a lived experience. Heidegger (1967) refers to these influences as *fore-structures* or the ideas and history that influence an investigator's interpretations (Laverty, 2003; J. A. Smith et al., 2009).

Researchers using hermeneutic phenomenology make the point that one cannot simply eliminate or "bracket out" these fore-structures (van Manen, 1997). The phenomenon known as *hermeneutic circles* helps to illustrate how the researcher's preconceptions (i.e., fore-structures), and/or their consideration of the many contexts, influence their interpretations of the data (Packer, 1989). These interpretations involve considering relationships between the whole of the data collected and individual parts of these data (J. A. Smith et al., 2009). For example, using this hermeneutic approach, I may consider how a participant's story of their service provider talking on the phone (individual part) is an example of interprofessional collaboration, and then I might consider how my previous experiences in the organizations under investigation, my readings on collaboration, and other research participants' accounts have led me to see this particular story of a phone call as an example of interagency collaboration. The main emphasis of hermeneutic phenomenology is on developing a description of a phenomenon while illuminating the perspective that informed this description.

Van Manen (1997) provides methods to organize an inquiry informed by the hermeneutic circle by discussing how hermeneutic phenomenological research moves dynamically between several research activities. These activities follow from the researcher identifying a phenomenon (e.g., service users' experiences of interagency collaboration) and the researcher's particular interest in this phenomenon. Following a consideration of what is involved in the phenomenon of interest, the researcher then conducts an inquiry with people who have experienced this phenomenon, and then interprets the descriptions he or she has elicited (van Manen, 1997). The researcher then considers these interpretations in light of his or her assumptions and their prior knowledge of the phenomenon (Creswell, 2007; Laverty, 2003). According to van Manen (1997), in the data collection phase, the researcher reflects on essential themes in the data and refines his/her description of the phenomenon through writing and re-writing, which enables the researcher to maintain an orientation to the phenomenon and to constantly consider how each experience relates to it. The final product of a hermeneutic phenomenological investigation

includes a description of the phenomenon under investigation in relation to the assumptions and pre-understandings of the researcher.

In my investigation, I am presenting a social constructionist perspective on interagency collaboration as both an engaged service provider and a researcher interested in service users' experiences of the phenomenon of receiving care shared between the Community Agency and the Children's Hospital. In order to illuminate this perspective, I focused on professional cultures, which I described in Chapter III as consisting of unique discourses, associated with particular professional settings, that include unspoken rules and resultant social practices (Burr, 2003). Professional cultures exist within specific organizations, where particular unspoken rules and social practices predominate. These professional cultures influence the traditional ways that particular professionals within an organization relate to their clients and to other organizations. These traditional ways of relating may be informed by cultural discourses that investigators can make visible by tracking what is included and what gets left out of particular social interactions (Lock & Strong, 2010). For example, the lack of conversations about the social contexts of service users in a hospital-based psychiatric service may reflect a dominant discourse that supports assigning biomedical causes to mental health difficulties. When this is compared to a lack of discussion about biomedical causes in a community mental health service context, these exclusions together may point to different foci or accepted knowledge regarding the causes, and related treatments, of mental health difficulties in the practices of each of these professional cultures.

In this investigation, I seek to understand the service users' experiences of interagency collaboration based on a young person's psychiatric diagnosis involving both the Community Agency and the Children's Hospital. Following a hermeneutic phenomenological approach, the fore-structures I illuminate in my findings include my experiences of these two organizations as well as literature on interagency collaboration and continuity of care that shaped the questions I asked. These various fore-structures influenced my research process that involved progressively richer explorations of service user experiences of interagency collaboration over three stages. My analysis embodied the hermeneutic circle of inquiry, which I describe further in my methods section below. My study involved three stages:

- Stage I: learning about service user experiences of interagency collaboration by interviewing veteran young people and their families with lived experience of this phenomenon;

- Stage II: Draw on such learning to investigate the experiences of a second group of young people and their families as they initially became engaged in the experience of interagency collaboration; and,
- Stage III: presenting my initial interpretations of these participants' experiences of interagency collaboration to service providers engaged in interagency collaboration.

In what follows, I describe the setting of the research as well as the evolution of my research protocol through an account of changes made over time in response to ethics committee input. This will be followed by details of my three stages of research, by describing my participants, data collection, and analysis procedures.

### **Setting**

**Background of the agencies.** The Children's Hospital and the Community Agency were both established as a result of community initiatives in River City, but came from very different traditions of public service. The Community Agency is over fifty years old and was originally established to "promote the general welfare of youth and to act as a clearing-house for youth needs and services" (Community Agency, 2010). The Children's Hospital celebrated their 40<sup>th</sup> anniversary in 2014, and grew from a community-established general children's hospital into a regional teaching hospital that provides a wide range of services for children and youth within a large geographic region of Ontario. The Community Agency and the Children's Hospital have each taken leadership roles in River City regarding the mental health of children and youth; both are at the forefront of many collaborative initiatives. For example, in the early 2000s, staff at the Children's Hospital pursued partnerships with other community organizations, including the Community Agency. Within this new partnership, the Community Agency began to provide crisis follow-up via phone, or in person, to youth who had presented to the Children's Hospital Emergency Department, as well as counselling support for youth following their inpatient admission at the Children's Hospital. These new arrangements replaced the previously decentralized practice of consultations by Children's Hospital staff members being offered to many surrounding child and youth mental health services, which included the Community Agency. Partnerships between the Children's Hospital and the Community Agency became official (formalized) in 2009, and culminated in 2014 with a program that integrated staff from the Community Agency, the Children's Hospital, and the Mental Health Hospital into a specialized service for youth requiring intensive outpatient support.

At the time that I began my investigation, efforts towards establishing a system of care in River City began to align with Ontario-wide initiatives to establish a continuum of mental health care for all children and youth in Ontario and to improve mental health services for them through collaborations between agencies (Ministry of Children and Youth Services, 2006; Mulvale, Abelson, & Goering, 2007). In the context of these changes, and my experiences with the Children's Hospital and the Community Agency, I became interested in how families experience service providers from different organizations sharing their care or collaboration between service providers at the Children's Hospital and the Community Agency. I therefore proposed research to intensively investigate the increasingly interacting professional cultures of the Children's Hospital and the Community Agency.

### **Ethics Processes**

I originally proposed an ethnographic case study involving participant observation of intake interviews and intensive interviews with families currently receiving mental health treatment. The design of this project evolved in response to a number of external factors or contingencies (see Appendix A for specific changes). This evolution reflects processes intrinsic to qualitative research, which as Creswell (2009) writes, is *emergent* research so that elements of the research situation, including intended participants and data gathering techniques, shift as investigators learn more about their specific topics. I describe and reflect upon the constraints I encountered in regards to my original research plan in Chapter V. For now, it is important to note that, despite the modifications to my original research design, I was able to retain a focus on processes of interagency collaboration and continuity of care. In my original design, I also focused on capturing the evolution of families' experiences, informed by interviews of research participants with lived experience of this care, as they engaged in treatment shared between the Community Agency and the Children's Hospital. Given the exclusion of participant observation from my final research protocol, I also turned from ethnographic methods to a hermeneutic phenomenological analysis. I received approval from the Children's Hospital's Research Ethics Board, the Community Agency's Research Ethics committee and the Research Ethics Board of my home university to conduct the procedures that follow.

### **Methods**

#### **Participants and Recruitment**

Here we are reminded that contemporary investigations of interagency collaboration and continuity of care in children's mental health services are multidimensional and involve

participants who speak from multiple perspectives. Consequently, I recruited study participants who offered a variety of perspectives: veterans of treatment, families currently engaged in treatment, and service providers. The use of multiple informants extends previous research into continuity of care and interagency collaboration that rely on multiple informants. For example, in a recent Ontario study on continuity by Tobon et al. (2015), the investigators also included the views of parents, young persons, and service providers. In line with the hermeneutic process of progressively gaining richer understandings of my data, I designed three stages that built upon each other to provide a deeper understanding of families' experiences of interagency collaboration.

**Stage I.** In the first stage of my research process, I planned to conduct focus group interviews with young people and their parents who had lived experience of shared mental health treatment to establish themes for later exploration with in-depth interviews. Stage I of my research represented an exploratory stage in which I learned about the field of paediatric collaborative mental health care in River City.

I recruited four adolescents (16 years of age and older) and their families who were at least six months removed from when they received their diagnosis and began collaborative treatment for psychiatric difficulties. Unfortunately, one of these adolescents declined to participate. I used a purposive sampling method, aiming for maximum variation in cases (Roy et al., 2015; Yin, 2016) for this population due to my recruiting these youth through their service providers and the inherent vulnerability of youth who have received intensive mental health treatment. In order to assure that youth would be able to participate in a focus group interview, I excluded youth diagnosed with a psychotic disorder or who did not have a minimal level of reading. I also wanted to ensure that the families I spoke to were not in acute crisis, I therefore excluded families under active investigation by child protective services (please see recruitment presentation slides in Appendix D for specific recruitment criteria). I recruited these young people and their families because their stories represented "typical cases" (Creswell, 2007; Miles & Huberman, 1994) of adolescents who had experienced collaborative care for mental health problems (adolescent veterans) based on my experience in the field and literature on the epidemiology of mental health difficulties in youth. In order to ensure that they were immersed in interagency collaborative care, I sought families who had been treated previously for at least six months by the Children's Hospital and who had contact with the Community Agency for at least six months concurrent to or following their initial contact with Hospital services.

The characteristics of the Stage I sample are listed in Tables 1 and 2, below. The families were recruited by members of two teams based at the Children's Hospital, and one team based at the Community Agency following presentations in which I described my research (see Appendix D). Families had been asked by their service providers to sign Consent to Contact forms (see Appendix C). I then telephoned the families who had volunteered, explained the study to them, and emailed them Consent to Participate forms. Once the families had signed these forms, I convened two separate focus groups, one for parents and one for youth. I scheduled and organized these focus groups via email polls. I also interviewed parents and youth who were unable to attend their respective focus groups.

*Parents.* I collected data from a total of five parents, drawing from one focus group (n=3 participants) and one interview with a couple (n=2 participants). These parents provided the following demographic information on forms distributed at the beginning of their interviews (see Appendix B).

Table 1

*Stage I parents' demographic characteristics (N=5)*

| Characteristic                                      | Values    |
|-----------------------------------------------------|-----------|
| Age range                                           | 45-62     |
| Female: Male                                        | 4:1       |
| Community College: University or above              | 4:1       |
| Married: Single parent                              | 3:1       |
| Employed: Retired                                   | 4:1       |
| Family History of Mental Illness: No family history | 4:1       |
| Range of time since child's diagnosis               | 2-12 yrs. |

*Adolescent veterans.* I collected data from three youth: two males and one female. One male and one female youth participated in what I had planned as a "focus group".<sup>9</sup> I interviewed the other male youth individually. These young people provided the demographic information listed in Table 2, below.

<sup>9</sup> While originally planned as a focus group, this instance took the form of a multi-informant interview when one youth had to re-schedule at the last minute.

Table 2

*Stage I youth demographic characteristics (N=3)*

| Variable                                         | Values                        |
|--------------------------------------------------|-------------------------------|
| Age range                                        | 16-18                         |
| Female: Male                                     | 1:2                           |
| Diagnoses (self-reported)                        | ADHD, Depression/ADHD, unsure |
| Taking medication: Not taking medication         | 2:1                           |
| Receiving counselling: Not receiving counselling | 2:1                           |

**Stage II.** Following Stage I, I recruited families who were becoming engaged in collaborative care. I delivered presentations to the service providers of two Children's Hospital and one Community Agency teams regarding my research and recruitment criteria (see Appendix D). Members of these teams then approached their client families and asked appropriate families to volunteer to be contacted. As a result of these service providers' efforts, I recruited three new-to-treatment client families. The main criterion for families' inclusion was engagement with either the community-based team or a hospital-based team and initial contact with the other service providers' team. The Community Agency serves an adolescent population twelve years of age and older, therefore, I limited my recruitment of participants to ages 12-14 at initial referral. I limited recruitment to youths under 14 years of age to better capture young people who were first accessing the services of the Community Agency and to reflect the lower range of the average ages of youth accessing acute mental health services in River City (Cloutier et al., 2010). Service providers from the Children's Hospital or the Community Agency teams approached these families to complete a "Consent to Contact" form (see Appendix C). I then followed up with the families who had completed the form and asked them to fill out consent forms. These families represent a "criterion sample" (Creswell, 2007; Miles & Huberman, 1994) in that they had all been followed by the Community-based team and were in the process of commencing services with a Children's Hospital based team. In seeking families commencing services with the Children's Hospital, I sought participants who were moving from care delivered by one organization to care that necessitated collaboration between the two professional cultures that are the focus of my research. I recruited one two-parent family and two single-parent families for this stage of the research, for a total of four parents. Each family was compensated \$50 per research interview. The family characteristics are described in Tables 3 and 4, below.

Table 3

*Stage II parents' demographic characteristics (N=4)*

| Characteristic                                      | Values |
|-----------------------------------------------------|--------|
| Age range                                           | 39-51  |
| Female: Male                                        | 2:2    |
| High School or less: University or above            | 2:2    |
| Married: Single parents                             | 2:2    |
| Employed: Unemployed                                | 3:1    |
| Family History of Mental Illness: No family history | 2:2    |
| Range of time since child's diagnosis (yrs.)        | 1-3    |

Table 4

*Stage II youth demographic characteristics (N=3)*

| Characteristic                                   | Values                        |
|--------------------------------------------------|-------------------------------|
| Age range                                        | 13-14                         |
| Female: Male                                     | 3:0                           |
| Diagnoses                                        | ADHD, Depression/ADHD, unsure |
| Taking medication: not taking medication         | 3:0                           |
| Receiving counselling: Not receiving counselling | 3:0                           |

**Stage III.** For the final stage of my research, I e-mailed all members of the two hospital- and one community-based teams inviting them to participate in an in-person focus group. Subsequently, I met separately with each of the three clinical teams. Each clinical team was offered a snack (up to a \$50 value) to be shared during their focus group interview, as an appreciation for their participation. Clinical team members' characteristics are listed below. Unfortunately, community-based team members were unable to fill out demographic questionnaires due to organizational constraints. These participants' characteristics are therefore less complete than their hospital-based counterparts and are based on my familiarity with the persons who participated in the focus group and the genders that they identify as.

Table 5

*Stage III Community-based service providers' demographic characteristics (N=8)*

| Characteristic     | Values            |
|--------------------|-------------------|
| Age range          | Data not provided |
| Female: Male       | 6:2               |
| Profession         | Data not provided |
| Years in the field | Data not provided |

Table 6

*Stage III Hospital-based service providers' demographic characteristics (N=14)*

| Characteristic                            | Values  |
|-------------------------------------------|---------|
| Age range                                 | 28-77   |
| Female: Male                              | 10:4    |
| Profession SW: OT: Psych: MD <sup>1</sup> | 3:1:5:4 |
| Years in the field                        | 4-30    |

1. SW=Social Worker, OT=Occupational Therapist, Psych=Psychologist and MD=Medical Doctor.

**Data Collection**

In my investigation, I sought to explore the ways that service users experienced two professional cultures based on the current status of interagency collaboration in River City, to expand upon the existing research literature regarding interagency collaboration and continuity of care, and to track collaboration between these two cultures. I used a three-stage data collection process where I learned about, tracked, and elicited reflections on various families' experiences of interagency collaboration. I summarize these techniques in the figure below followed by descriptions of my data collection and analysis by stage.

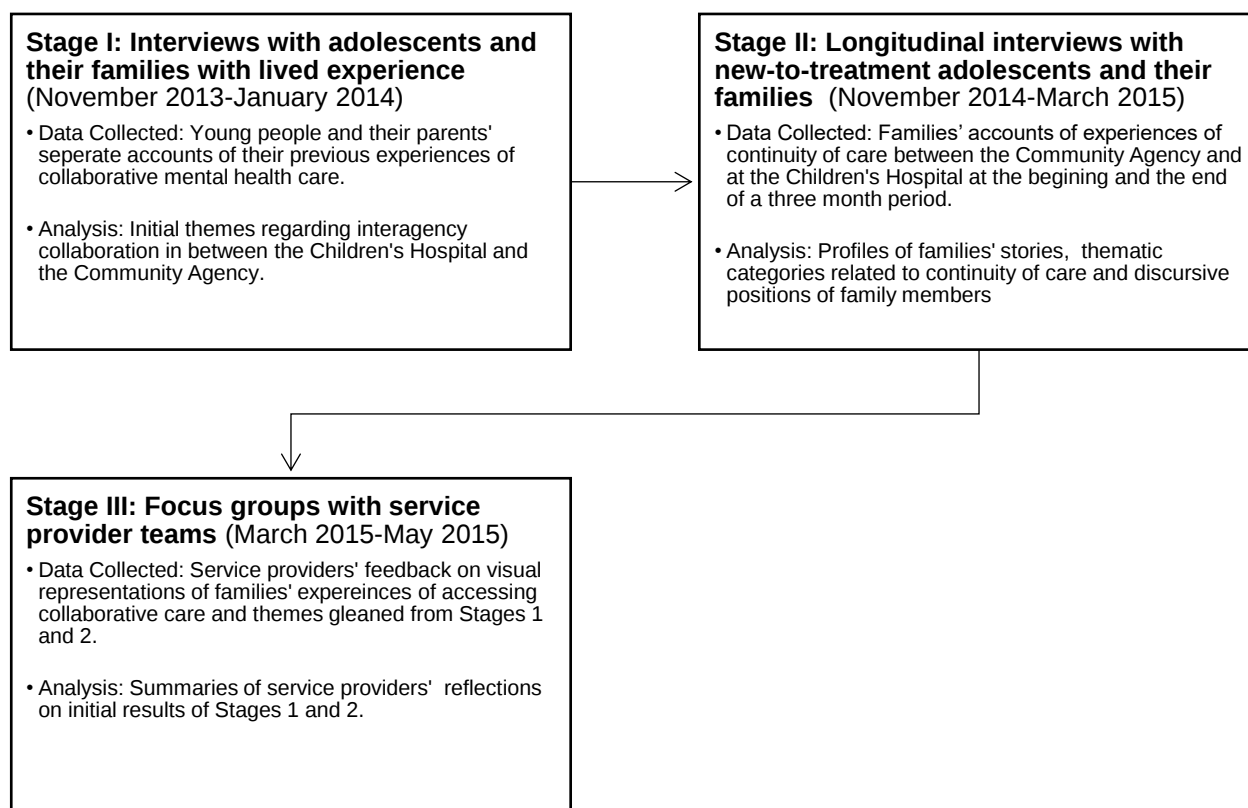


Figure 1. *Data collection and analysis listed by stage. This flow-chart describes the three stages of data collection and analysis*

**Stage I: Interviews with adolescents and their families with lived experience.** In Stage I, I asked about adolescents and their families' previous experiences of collaborative care in the context of a psychiatric diagnosis (see Appendix B for interview guides). I organized two separate ninety-minute focus groups: one for youth, the other for parents. Both focus groups were held in my home University's conference rooms. Parents and youth were provided with pizza and drinks. One set of parents and one youth who could not attend the focus groups were interviewed individually. The purpose of these focus group interviews was to ascertain young people and their parents' separate descriptions of these youth receiving collaborative care shared between the Children's Hospital and the Community Agency. I was particularly interested in the extent to which they saw services as coordinated following from a psychiatric diagnosis.

I selected focus groups as a data collection tool in order to generate themes for more in-depth explorations in the later part of my research, and to later contextualize my findings (Groleau, Zelkowitz, & Cabral, 2009). In general, focus groups provide an opportunity to observe strangers interact regarding a topic of interest, in a short period of time, and allow for the observation of similarities and differences in participants' opinions (Morgan, 1997). In the case

of the present research, focus groups provided an opportunity for me to co-construct meanings of the concepts of interagency collaboration and continuity of care with research participants (Duggleby, 2005). Many authors counsel the use of homogenous focus groups (i.e., participants of similar ages and background experiences) and consisting of four to six youth participants (Heary & Hennessy, 2002; Peterson-Sweeney, 2005) or up to 12 participants in the case of adults (Kitzinger, 1995; Morgan, 1997; O'Donnell, Lutfey, Marceau, & McKinlay, 2007). Following this advice, in Stage I, I planned to conduct separate interviews with youth, aiming for four youth in one focus group and the parents involved with these youth in another. These groups provided an ideal environment to observe and contribute to the social construction of ideas, creating an environment to allow research participants to work together to understand and construct meaning about the world in a particular time and place. I used the same questions, modified appropriately for adults or for youth, in both individual and focus group interviews (see Appendix B).

These questions<sup>10</sup> were designed to elicit the young people's and their parents' experiences of collaborative care following their prolonged exposure to such care. Following focus groups in Stage I, I met with the two research assistants who had assisted me by making notes on the content of these focus groups, and we discussed our general impressions. I recorded these observations along with the general notes that my research assistants had taken during these groups. I did not have assistance in conducting the parental dyad in-person interview nor in the individual youth telephone interview. The families' responses to Stage I questions shaped my Stage II data collection through a process of data analysis and discussion with my research supervisor discussed further, below.

*Member checks.* After Stage I, I conducted brief member checks by e-mailing summaries of the interviews/focus groups to Stage I participants (see Appendix E for a sample summary). I asked research participants to read over these summaries and to comment on any statements that they felt the researcher may have misrepresented. Out of the three youth and five parents I emailed, I received one response from a parent, who chose the pseudonym, Karen and clarified her wording regarding an experience of missed care when discussing the Children's Hospital—she clarified that she understood the Children's Hospital staff to be overstretched instead of

---

<sup>10</sup> Questions for Stage I were generated from a review of previous investigations on illness experience and continuity of care (Groleau et al., 2006; Ware et al., 1999) and were designed following a method described by Groleau, Zolkowitz, & Cabral (2009) to assist research participants in recalling past experiences of help-seeking.

unresponsive to calls from the Community Agency. I subsequently changed the transcript (to reflect this (see Appendix E for the final transcript)).

**Stage II: Longitudinal interviews with new-to-treatment adolescents and their families.** Stage II involved two separate interviews with three new-to-treatment families receiving services from the Community Agency team and beginning with a Children's Hospital team. I modified my semi-structured interview guides based on findings from Stage I interviews, which I discuss at the end of Chapter V. These findings allowed me to focus on more deeply understanding the aspects of interagency collaborative treatment that Stage I respondents recalled as most impactful. I used these findings to modify the following interviews:

1. An initial, semi-structured interview where I inquired into families' perceptions of continuity of care in their paths to, and hopes (expectations) for, their collaborative mental health treatment (see Appendix A). This interview was based on questions used for ethnographic research on illness experience including psychiatric diagnoses (Groleau, Young, & Kirmayer, 2006). I refined the focus of these questionnaires following analysis of Stage I interviews (see Appendix B for Interview Guide).
2. A second interview concerning families' experiences of their previous three months of treatment. Semi-structured interview questions were based on ethnographic and quantitative research on continuity of care (Haggerty, Roberge, Freeman, & Beaulieu, 2012; Tobon et al., 2015) combined with questions informed by Seidman's (2006) sequence for tracking the evolution of an experience; in this case, the progression of treatment for a psychiatric diagnosis (see Appendix B for an Interview Guide).

The purpose of Stage II was to elicit stories of these families' experiences of the mental health system in the context of the young person and his or her family's understanding of a psychiatric diagnosis with a particular focus on continuity of care. I describe the analysis of these stories in the next section. I conducted all interviews in locations of the families' choosing. Consequently, I met one family at my home University, and interviewed the other two families in their homes. Stage II lasted approximately 5 months.

**Stage III: Focus Groups with service provider teams.** In preparation for Stage III, I used two techniques to make data easily accessible to service providers who participated in three separate focus groups. I used the following techniques to represent my data:

- a) making a visual representation of families' treatment journeys (timelines) that depicted the stories of Stage II families, and
- b) mapping participants' points of view on collaborative care, based on Clarke's (2005) "positional map," to depict research participant families' experiences in the context of their mental health treatment journeys.

To construct timelines based on families' stories, I borrowed from the practice of mental health journey mapping that other researchers have used to illustrate how families move through mental health systems (Jones et al., 2009; NHS Institute for Innovation and Improvement, 2008). I created these timelines for the service providers involved in the care of the families I interviewed in Stages I and II in order to demonstrate how these families described their entry into services and subsequent experiences of shared care between service providers. I created two sorts of timelines, one depicting *entry to services* and the second, *travels through the system*. Following Clarke (2005), I also constructed a *positional map* to summarize my thematic analysis of the points of view that families expressed on interagency collaboration in Stages I and II.

In Stage III, I presented the timelines and the map (see Appendix H) in person to each of the three clinical teams. I designed these consultations to stimulate service provider's responses to my initial analysis of the data and to provoke elaboration on the data I had already collected in Stages I and II. To mask client family identities, specific quotations from families were not used in presentations to practitioner focus groups. I used a semi-structured interview guide for these focus groups (see Appendix B).

### **Data Analysis**

To organize the data I had collected, I created transcriptions of all recorded interviews from Stages I and II, either on my own or with the help of research assistants. I stored all transcriptions, as well as the audio recordings of my Stage III focus groups, in ATLAS.ti, a computer-aided qualitative data analysis software program. Given that I used these consultations to contextualize my previous results, I did not transcribe the audio recordings of these conversations, but rather listened to them and took notes. To analyse these transcripts and audio recordings, I followed van Manen's (1997) selective reading approach where in Stages I and II, I read each transcript, and in Stage III I listened to the audio recordings of focus groups, multiple times. While reading transcripts, and listening to audio recordings, I considered "what

statement(s) or phrase(s) seem particularly essential<sup>11</sup> or revealing about the [experience] being described?” (p. 93) In particular, in Stages I and II, I was interested in statements or phrases in which participants described elements of their experience of interagency collaborative care regarding a psychiatric diagnosis and in Stage III, I was interested in respondents’ reactions to my initial analysis as these reactions related to their experiences of interagency collaborative care.

After I identified these significant statements, I grouped them into categories to which I assigned codes using the in vivo coding function of ATLAS.ti. In this way, I could identify statements that fit into particular categories across transcripts in the first and second stages. Once I had identified a number of codes I considered how these codes related to each other and tried to merge codes together in cases where their meanings were closely matched.

Having organized these significant statements under a number of codes, I then looked for relationships among the codes and assigned theme titles to clusters of codes. These themes were represented as phrases that captured fundamental<sup>12</sup> meanings of the experience under investigation in the contexts that these meanings were developed (Creswell, 2007; Saldana, 2012). In particular, I considered how connections I drew between codes related to my experiences in the field and the literature I reviewed in Chapter II.

Here is an example of the process I used to develop these groups of codes into themes. On my first reading of the transcripts of Stage I interviews, I identified several passages of text that related to parents’ and young people’s dissatisfaction with the services they had received. I originally coded these significant statements as *dissatisfaction with services*. Following discussions with my research supervisor, I came to realize that this code was too broad and did not relate directly to collaborative care. I then revisited the statements, assigning several codes, all of which related to young persons’ and their parents’ dissatisfaction with services shared between various workers. These codes included *family as case managers*, *inaccessibility of services*, and *interactions with individual workers*. I then related these codes to literature in which authors report aspects of family members’ dissatisfaction with services. I considered these

---

<sup>11</sup> While van Manen (1997) talks of “essential” phrases and statements, in my analysis I looked, following a social constructionist view of what appeared most important in the context of the conversation at the time. In this way, I considered statements that were most resonant to the experiences being described but I did not see these statements as representing the truth of the participant’s experience.

<sup>12</sup> When using the word “fundamental” I refer to my process of considering what research participants told me was fundamental to the experiences I inquired about as opposed to seeking a fundamental meaning of their experience.

sources in combination with my experience of meeting families who were receiving collaborative care, as a crisis intervention worker, and as a student at the Community Agency. From my reflection on these various sources of information, I noticed that in Stage I, when it came to speaking about being dissatisfied, young people typically spoke about their individual encounters with service providers whereas their parents spoke about their struggles with accessing and managing their children's services. I related these findings back to research results that describe service users' frustrations when undergoing multiple assessments (O'Reilly et al., 2013) and large scale studies of family help-seeking that show families accessing multiple services at once for the same problem (Reid et al., 2009). This combination of sources led me to group the codes into two themes: 1. Repeating stories, and 2. Collaboration is about feeling heard. These two themes encompassed several related codes in the Stage I transcripts.

This process of moving from significant statements to codes and then to themes was continued in the second stage as well. I used the Stage I codes and themes which arose during my induction into the research context through my encounters with the Children's Hospital and the Community Agency to inform the development of codes and themes in Stage II. In turn, the codes and themes associated with both Stage I and Stage II of the project stimulated the conversations that contributed to my Stage III findings. These three key phases of data analysis are outlined below.

**Stage I.** To prepare for my in-depth interviews in Stage II, I identified initial themes through my analysis of the results of Stage I data collection. Given that the purpose of my Stage I interviews was to learn about veteran families' experiences of collaborative care in River City, I refer to the themes generated in Stage I as "initial" because I used these themes to shape my analysis of more specific experiences of interagency collaborative care as shared by new-to-treatment families in Stage II. My identification of these initial themes and subsequent refinement of these themes in Stage II (which I will describe in more detail below) was the result of a hermeneutic process (Ajjawi & Higgs, 2007) where my analysis moved from a focus on individual data points (assigning codes to passages) and reflecting on my work experiences to a broader understanding of interagency collaboration, the phenomenon under investigation (Packer, 1989). In Stage I, I used the following to inform this broader initial understanding of interagency collaborative care in River City:

- reflections on my experiences in the Community Agency and the Children's Hospital,

- immersion in the data through identifying passages and assigning codes,
- discussion of the codes with my research supervisor,
- considering the relationships between similar codes based on my readings regarding and experiences of interagency collaborative care.

In my analysis, I used the concept of the hermeneutic circle, which Ajjawi and Higgs (2006) describe as “a metaphor for understanding and interpretation, and which involves a movement between parts (data) and a whole (evolving understanding of the phenomenon) where each part and movement gives additional meaning to the other, so that understanding is circular and iterative” (p. 623). I assigned codes to multiple passages of text related to families’ experiences of interagency collaboration regarding a child’s psychiatric diagnosis, and then grouped the codes under themes, informed by my reading of literature related to interagency collaboration and my experiences in the field before, during, and after my data collection process. When coding the transcripts, I identified and coded families’ descriptions of their experiences of interagency collaboration regarding a psychiatric diagnosis. I carried these codes over from one transcript to the next using ATLAS.ti. As I coded more transcripts, I modified existing codes in ATLAS.ti to correspond to other similar passages. My modified codes reflected my evolving understanding of interagency collaborative care informed by the interviews, my reading of the literature, and my experiences with the agencies under investigation.

Following a hermeneutic process of reflecting on the data I collected, I shared transcripts of the youth and parent focus groups with my research supervisor. Following a hermeneutic phenomenological methodology, my research supervisor and I discussed and debated the fundamental meanings that research participants were trying to convey from my research supervisor’s perspective as a social constructionist counsellor and theorist and from my perspective as a service provider in psychiatry as well as a social worker—a position where I am well-acquainted with a tension between a focus on context and a search for a definitive diagnosis. Over time, we discussed the passages and associated codes, gradually developing a more nuanced understanding of codes I assigned to participants’ statements. To portray this deeper understanding of the phenomenon of participants’ experiences of interagency collaboration, I summarized the connections I drew between codes based on my experiences of the Community Agency and the Children's Hospital and knowledge gleaned through readings regarding interagency collaboration. I used these reflections to create themes that encompassed a number of similar codes. The list of themes I developed at the end of Stage I demonstrates my

increased understanding of the context of collaborative care between the Children's Hospital and the Community Agency that I drew from as I began data collection in Stage II

**Stage II.** As I described in Chapters I and II, the system for delivering children's mental health care in Ontario has evolved considerably in recent years. Distinct and separate systems of hospital- and community-based care have been integrated into a unified system of care for children and their families. So, whereas continuity of care used to be achieved mostly through delivery of service within the hospital, now it calls for interaction with a variety of services in the community. As a result, the concept of continuity of care now also involves collaboration between diverse practitioners. In the Stage I analysis, I described families' perspectives on interagency collaboration and found that a key aspect of their recalled experiences was that of how their service providers shared information. In Stage II, I investigated the detailed interactions between practitioners focusing specifically on families' experiences of a specific dimension of continuity of care, informational continuity, between the Children's Hospital and the Community Agency. I will present these families' experiences through:

- profiles of each family and the service providers whom they described as being involved in their care; and
- themes gleaned from interviews with families in Stage II, informed by literature on interagency collaboration and informational continuity.

Guided by my discussions with my research supervisor, my Stage I findings, my research questions, and my previous reading regarding continuity of care, I interviewed families in Stage II regarding their experiences of beginning, and engaging, in collaborative treatment related to a mental health diagnosis. Following my Stage I results, I took included notes in my semi-structured interview guides for Stage II to act as prompts to further inquire into new-to-treatment families' experiences of informational continuity and interagency collaboration. To track their experiences, I interviewed these families at the beginning, and at the end, of a three-month period. During the time between the first and second interviews, I reviewed the transcripts of the first interviews and the notes I had taken following these first interviews. I used these sources of data to note significant events in families' experiences and the hopes they had expressed for their treatment processes in three months' time. I also shared the audio recording and transcript of a first interview with my research supervisor. In my subsequent interviews with families, I noted what had changed about their story from their first interviews, and I noted how these changes related to families' descriptions of continuity of care.

To assist with analysis, and to provide readers with a picture of the family research participants, I constructed one *profile* per family to summarize each family's entry into collaborative mental health care. In creating these profiles, I was inspired by the writing of Seidman (2006), whose research design tracked the evolution of an experience, and which informed my interview questions for Stage II. He described a method of presenting interview results by creating profiles based on the words of individual interviewees that highlight their descriptions of their experience of the phenomenon under investigation. In my research design, I modified Seidman's (2006) profiles to act not as findings, but rather as an introduction to the stories of the families who were the participants of my Stage II interviews. My profiles portray young people and their families' descriptions of their diagnoses and how service providers became involved in their collaborative care journey. The profiles consist of quotations from participant families that I assembled into a story of their experience to add context to my later exploration of these families' descriptions of continuity of care.

Using these family profiles, I illustrate the context of statements by Stage II families that I later coded and used in combination with my learnings from Stage I and my previous review of the literature to construct themes. Following from my realization of the importance of informational continuity as a result of my Stage I interviews, I focused on significant statements where families described social practices related to informational continuity enacted by service providers from the Community Agency and the Children's Hospital, and I assigned codes to them. I identified codes based on passages of text that related to informational continuity and then, reflecting the process of the hermeneutic circle, shared these codes and associated passages with my research supervisor. Following his feedback on these individual codes and associated passages, I analysed these codes in relation to informational continuity and sorted these codes into themes. I specifically described passages that fit with previously existing descriptions of continuity of care, the phenomenon which I had planned to focus on in this stage and specifically informational continuity that I focused on as a result of my investigations in Stage I.

As I gained a holistic understanding of families' experiences of continuity of care, I developed themes from these codes. Following from my findings in Stage I, I used the dimension of informational continuity to inform the development of these themes and my findings generally. Informational continuity involves service providers' processes of sharing information across professional cultures to ensure smooth transitions between their respective service. The themes I generated in Stage II reflected families' experiences of this information sharing.

As I described in Chapter III, I was particularly interested in families' experiences of interactions between members of the respective professional cultures of the Children's Hospital and the Community Agency. In order to connect each interaction families described in Stage II with a respective professional culture (i.e., hospital or community), I considered the themes I identified in Stage II, and I then compared them to the initial themes I identified in Stage I. In comparing sets of findings from Stages I and II, I looked for indications of professional cultures that as Hall (2005) describes reflected "values, beliefs, attitudes, customs and behaviours" (p. 188) which resembled indications of Kleinman's (1978) comparison of healthcare and religions as both consisting of "... symbolic systems built out of meanings, behavioural norms, and the like" (p. 86). In this case, I looked for unique actions and statements that indicated the professional cultures of the Community Agency and of the Children's Hospital, and I was able to distinguish a number of statements particular to each. I used these statements to illustrate and compare particular practices used by service providers working respectively at the Children's Hospital and the Community Agency. I then used these comparisons to speculate upon discourses that inform the practices of service providers working at each organization.

As a culmination of my Stage II analysis, I produced visual representations of my initial analyses in the form of two timelines and a positional map. In the timelines, I illustrated how the families described entering the children's mental health system and journeying through it, and I also represented the profiles of participants that I developed in Stage II. In the positional map, following Clarke (2005), I charted the different points of view that families offered on collaborative care throughout the data collection process. I used the slides of both the timelines and the positional map (see Appendix H) as visual aids to summarize my initial findings on collaborative care and to provide prompts for the verification and elaboration of my data in Stage III.

**Stage III.** In the final stage of my inquiry, I relied on audio recordings of the focus group interviews with service providers from the Community Agency and the Children's Hospital using the timelines and positional map I described above as visual prompts. I then stored the recordings in ATLAS.ti so I could highlight relevant passages of speech by timestamp and transcribed only those highlighted passages to identify specific comments that the Stage III service providers had made regarding the timelines and the positional map regarding my initial impressions of the results from Stages I and II of my inquiry. I use the specific quotes and summaries of the Stage III focus groups in Chapter VII. In Chapter VIII, I discuss my results and compare them to the

results of research that was carried out by staff at the Children's Hospital regarding families' experiences of the mental health system in River City (Children's Hospital, 2015).

The data analysis therefore unfolded in stages, with one stage informing the next. In Stage I, I learned about the field of collaborative care, with a dimension of continuity of care, informational continuity, emerging as a key theme. I then specifically focused on interactions associated with continuity of care in Stage II as experienced by Stage II research participants. In Stage III, I then enhanced my descriptions of these interactions by sharing my results with service providers and recording their responses.

### **Quality and Trustworthiness**

To ensure quality and trustworthiness in a qualitative inquiry, the researcher must build transparency into the methodology and analysis. My intention, which has been informed by emerging trends in postmodern research on service users' experiences of mental health treatment (Haene, 2010; Strong & Gale, 2013), has been to depict how my perspective on my research participants' experiences was influenced by my experiences in the field as a way of being transparent and allowing the reader to trust my results by being explicit about influences on my data collection. I used the combination of my perspective with those of research participants and service providers to engage in a hermeneutic inquiry, reporting and contextualizing the experiences of families who had received treatment through interagency collaboration and speculating upon the context of their experiences within the professional cultures of the Children's Hospital and the Community Agency.

### **A Contextualized Approach Grounded in Participant Experience**

In my work, I elicited multiple perspectives on the phenomenon of collaborative care. To demonstrate how I worked to ensure trustworthiness in my research design, data collection, and interpretation, I now provide a synthesis of Whittemore, Chase, and Mandle's (2001) work on validity standards in qualitative research, Morrow's (2005) work on constructionist qualitative research in counselling psychology, and Schwartz-Shea and Yanow's (2012) descriptions of qualitative research in relation to quantitative research to describe the primary criteria of:

- credibility and authenticity,
- criticality and integrity, and
- reflexivity.

I also describe, following Whitmore et al.'s (2001) secondary criteria of sensitivity, two further criteria specific to constructionist research as proposed by Morrow (2005):

- verstehen, and
- co-construction.

**Credibility and authenticity.** Whittemore et al. (2001) described credibility and authenticity as researcher behaviour that inspires confidence in a faithful interpretation in situations where the researcher works to reflect the experiences of the participants and to then interpret these experiences in a way that draws on information external to the researcher's experience. In particular, researchers need to show the participants' perspectives while accounting for their own interpretations. This criterion also encompasses "fairness," as proposed by Morrow (2005), in which the researcher "solicits and honors" different constructions of the data (p. 252). To achieve a credibility and authenticity that includes fairness in my collection and portrayal of research data, I conducted multiple member checks (e.g., sending descriptions to Stage I participants and contextualizing the research data in Stage III) and presented my initial interpretations to the research participants and their service provider teams. These procedures resulted in participants being able to comment on the data, which resulted in multiple interpretations for my later analysis. I was then able to demonstrate fairness by bringing forward and discussing research participants' interpretations alongside my own analysis.

**Criticality and integrity.** According to Whitmore et al. (2001), criticality and integrity refer to the investigator's ability to demonstrate a critical appraisal of data throughout a clearly defined research process, which allows the investigator to be reflexive (discussed further below), and to demonstrate that he or she collected and interpreted the data in a coherent manner. As I described in Chapter II, I used specific constructs to guide my data collection and interpretation stages. The constructs, interagency collaboration and continuity of care, allowed me to report on my data in comparison to existing data collected in similar settings. I also reflect on my experiences in the field in Chapter V, which allows me to demonstrate how my perspective evolved over time. By using multiple methods of data collection, and by collecting data from multiple sources, I was able to go over my chosen area of inquiry repeatedly, which allowed me to better understand the experience of collaborative care from multiple perspectives. Through my two stages of data collection and, one stage in which I checked the data with service providers, I looked at experiences of interagency collaboration from multiple angles. Using these methods of inquiry, I was able to both build on initial observations and to identify what data remained to be

integrated. I clearly delineated the various stages of data collection in this chapter, and in Chapters V and VI, I present my results sequentially in accordance with these data collection procedures. This transparent presentation of my results will allow readers to reflect upon my data collection procedures and my own critical appraisals of those data.

**Reflexivity.** Schwartz-Shea and Yanow (2012) describe two characteristics of reflexivity: the first involves researchers considering how their own personal professional status and position affect the accounts of the research they construct, and what they claim as knowledge based on these accounts; the second involves considering the professional communities the researchers belong to, and how these communities themselves are constructed. In regards to the first aspect of reflexivity, significant portions of Chapters I and V describe the context of my research and how I came to my particular research questions. In Chapter I, I portrayed my previous history in approaching the research topic through my initial investigations of ADHD and my subsequent interest in service providers from different professional cultures providing shared services as a means of opening up space for further collaborative dialogue. In Chapter V, I discuss how my own understandings of professional cultures, which are at the centre of this dissertation, were constructed, including referencing my own personal and professional positions. In regards to the second dimension of reflexivity, Chapter II presented the historical contexts of the constructs (interagency collaboration and continuity of care) that guided my investigation. I used these strategies to foreground the historical and moment-to-moment constructions of the professional and research contexts of my data collection and subsequent interpretation.

Whitmore et al. (2001) also provide a number of secondary criteria, the most significant of which, for this work, is the criterion of sensitivity. To consider this, I borrow from Morrow's (2005) specific criteria for constructionist research, *Verstehen* and *co-construction*.

**Verstehen.** To synthesize Whitmore et al.'s (2001) secondary criteria, I use Morrow's (2005) description of *Verstehen*, or the extent to which participant meanings are understood deeply. I demonstrated *Verstehen* in Chapter I when I described my induction into the field of collaborative mental health care, specifically how I came to refine the questions I asked about these experiences. I also reflected on the evolution of my perspective, which changed when I noticed that various psychotherapeutic models and understandings seemed divided along agency lines. I also provide further evidence for *Verstehen* in Chapter V, where I recount my experiences of learning in the field to demonstrate how I was inducted into the agencies that the participants described.

**Co-Construction.** In reference to constructionist research, Morrow (2005) proposes an additional criterion that concerns “the extent to which there is a mutual construction of meaning (and that construction is explicated) between and among researcher and participants, or co-researchers” (p. 253). The verification of and elaboration on my results that I conducted with research participants, including service providers, allowed me to co-construct the research data and interpretations with my participants.

Morrow (2005) further explains that the researcher can understand participants’ constructions of meaning by paying attention to “context, culture, and rapport” (p. 253). I address context and culture in my first data analysis chapter (Chapter V) where I describe my experiences of learning the field. There, I add further contextualization by describing my experiences within the different professional cultural worlds (i.e., within hospital- and community-based organizations) where the research took place. My reflections on these experiences demonstrate my initial understandings of the professional cultures involved, which are further informed by the conceptual bases discussed in Chapter III. Finally, I worked carefully with the research participants to establish myself as a researcher, as opposed to a clinician, to establish rapport through developing trust, as shown in the following excerpt from a research transcript:

*Catherine: I feel kind of bad for saying this ‘cause I’ve dealt with you at [The Children’s Hospital Emergency Department].*

*Noah: Well part of this is to help me learn and help other people learn how to do their jobs [correctly], right?*

In this interaction, I was working with a research participant, whom I had previously met as a clinician, to establish a different relationship, one in which we worked together to educate service providers by acknowledging our previous interactions and describing the benefits of the new roles we were taking on together. This approach helped me to establish rapport by acknowledging the participant’s experience and by demonstrating the importance I attached to their words.

In this chapter, I have shown the ways in which I have thought about and collected my data in congruence with social constructionist epistemology. I also described changes in my research protocol and described the resultant characteristics of my research participants. I then described the ways in which, following the six steps of Van Manen’s (1997) hermeneutic phenomenological approach, I conducted my investigation through explanations of:

1. Selection of the setting and participants to turn to the phenomenon of collaborative mental health care;
2. Data collection methods to demonstrate the steps I took to investigate this phenomenon as lived by research participants;
3. Data analysis by elucidating my co-construction of the data through interviews and focus groups to show how I reflected on essential themes through conducting multiple stages of research build upon each other;
4. Distillation of themes into writing through the data analysis process;
5. Establishment of credibility, authenticity, criticality, integrity, and reflexivity to maintain a pedagogical orientation to the phenomenon of collaborative care; and
6. My use of verstehen and co-construction to maintain a balanced relationship between parts of the investigation and my findings.

These six steps provided the groundwork for the consideration of my research results in Chapters V and VI, and my concluding discussion of those results in Chapter VII.

## CHAPTER V: EXPLORATIONS OF INTERAGENCY COLLABORATION AND PROFESSIONAL CULTURES

In this chapter, I describe my induction into the research context and the findings from my Stage I interviews with young people and their parents, which will subsequently inform Stage II. Findings from Stage I address the first of my research questions: How do young people and their families who are veterans of interagency collaborative mental health treatment describe their previous experiences?

To set the stage for these interviews, I first describe my learnings regarding the organizations I focused upon to study collaborative care. Similar to an ethnographic description of “entering the field” (Gobo, 2008), the history I describe includes my own learning about the Children’s Hospital and the Community Agency, because this learning influenced my reading of my interview participants’ responses. In ethnography, descriptions of entering the field consist of the researcher making explicit how they position themselves in *relation* to research subjects with whom they spent a significant amount of time through a particular “way of seeing”; that is, through specific *participant observations* (Wolcott, 2008). I did not conduct participant observations due to constraints I encountered in the field. However, I designed a study in which I situate my findings, such as the focus group results I present later in this chapter, in the context of how I developed my perspective on these results.

To recount the development of my perspective, I describe what I learned about interagency collaboration and the professional cultures of the two agencies implicated in this investigation during my student practicum at the Community Agency and my subsequent employment at the Children’s Hospital. I include these experiences because they coincided with planning my research and collecting the data, and my Children’s Hospital work continues as I write this dissertation. I also describe the process of seeking approval from these two agencies’ research ethics bodies to depict my multiple interactions with the professional cultures of these agencies. I reflect on how my experiences of the particular social practices of each professional culture informed my perspective. Next, I describe the results of my focus group and individual interviews with young people and their families regarding their lived experience of collaborative care. This chapter concludes with my reflections on lessons learned from my work and research experience.

**Being Inducted into the Children's Hospital**

I began employment in the Children's Hospital Emergency Department as a crisis intervention worker approximately three months after submitting my ethics applications and more than a year after I had concluded my student practicum at the Community Agency. My employment as a crisis intervention worker, which continued throughout my data collection process, influenced both my learning about the field and my perspectives on the Stage I interviews I discuss later in this chapter. In my crisis intervention role, I work in the Emergency Department and assess young people who present with mental health difficulties. As a crisis intervention worker, I am (as of this writing) responsible for making the decision, often in consultation with the on-call psychiatrist, as to whether these young people should be discharged with suggestions for community resources, referred to the hospital's outpatient services, or admitted directly to the hospital.

My determination rests on my assessment of the risk of harm presented by the specific young person's thoughts and behaviours. In this role, my colleagues and I are under intense pressure to ensure safety, and to make decisions about a young person's disposition in a short time period. We are often the only people from the Children's Hospital who families encounter. Given our roles as frontline representatives of the Children's Hospital, we dress in a business casual manner and conduct very structured assessments. My colleagues and I work in the language of diagnoses and assess levels of risk. As crisis intervention workers, we carry out our assessments in the context of a busy pediatric Emergency Department where the rooms we use have features such as escape hatches, panic buttons, and locking doors to assist us in responding to threatening behaviours. In keeping with this environment, furnishings are minimal and include clinically useful objects such as chairs that are very difficult to pick up or throw. In this hospital environment, noises—children crying and panic buttons beeping, among others—are loud and ubiquitous. We conduct our work in frequent consultation with psychiatrists and we rely on medical charts and assess problems in the context of psychiatric diagnoses and medications. In these interactions, we prioritize immediate safety, not the development of therapeutic relationships. The main purpose of our job is to ensure young people and their parents do not require further services from the emergency department after their visit.

At the hospital, my colleagues and I work from evidence based guidelines to respond to acute psychiatric problems and prevent suicide (Korczak, 2015; Shaffer, Pfeffer, & Work Group on Quality Issues, 2001). To follow these guidelines, we focus on assessing acute risk to help the

young person in our care using the least restrictive (Stroul & Blau, 2008), and most appropriate, means, up to and including involuntary hospitalization. The approach I have learned to take with the young people and families I meet in this role is a pragmatic one in which I rely on current psychiatric knowledge about risk factors for serious harm associated with mental illness. I fill out a standardized assessment form, and I work with my hospital-based colleagues and with external agencies to help families move forward from their Emergency Department visit. My interaction with each family is limited to one session, structured by particular assessment tools, and involves a clear goal: determining next steps from a clearly defined set of choices.

I have learned a significant amount about the responses to psychiatric problems available in a hospital-based environment. Our services are in high demand and my colleagues and I are tasked with the often immediate distribution of resources, such as short-term residential stabilization and extra school support. This situation stands in contrast to the community-based process of engaging in a system of care where presentations are made to a committee and the committee deliberates about the distribution of resources such as extra clinical support. Young people and their families do not currently access a *system* of care through the Emergency Department. Rather, our focus remains on preventing immediate harm, ensuring the safety of the young people whom we assess, and trying to avoid unnecessary psychiatric admissions. This balance often makes us the gatekeepers that families meet when they are most distressed. Therefore, I have seen directly how difficult it can be to access mental health services.

Kleinman (1978) characterizes the medical profession as a unique cultural system analogous to “kinship and religious systems, symbolic systems built out of meanings, behavioural norms, and the like” (p. 86). The description above demonstrates the utility of this metaphor; my account of the Children's Hospital setting and processes captures some of the intricacies of a professional culture—one which stands in sharp contrast to my experiences of the Community Agency, where ongoing counselling is the primary focus.

### **Learning about the Community Agency**

I completed a practicum at the Community Agency prior to collecting data for this dissertation, in a professional context strikingly different from my experiences of hospital-based work. Arriving at my placement, I found a small strip mall in a suburb of River City where the Community Agency's youth and family counselling team shared a building with a number of businesses. Their offices stood in sharp contrast to the sprawling hospital complex of glass and concrete, and could easily have been mistaken for the offices of any neighbouring business. The

Community Agency's offices, in contrast to the minimal and clinically necessary furniture in the hospital environment, contained furniture typical of the average small business. Artwork from former youth clients and bright agency posters featuring a diverse collection of youths offset the impersonal aspects of the location and furniture. Community Agency staff dressed in the casual manner exemplified by my supervisor, who sported a t-shirt and shorts. This setting promoted a hospitable environment and it was evident that the surroundings had been designed with clients' comfort in mind.

These surroundings and staff members' manner of dress provided a fitting backdrop for the community-based practices I learned in this placement. In contrast to the hospital-based focus on symptoms I described above, community-based practice prioritized client knowledges and resources. This emphasis on client competence reflect bodies of literature associated with the educational backgrounds of workers at the Community Agency. These experienced youth workers are trained in social work, counselling, and psychology, but not in medicine or psychiatry. My supervisor had a Bachelor's degree in Sociology and twenty years of experience working with young people and their families. His professional background contrasted with the hospital-based environment where many of my colleagues have advanced university degrees that often correspond to senior positions in the hospital hierarchy (e.g., physicians are team leaders).

In pursuing a placement at the Community Agency, I had hoped to learn more about counselling practices such as narrative and postmodern approaches which, informed by social constructionist ideas, position counsellors as co-editors alongside service users to co-construct their lives to fit better with service users' preferences and values. These approaches are based on bodies of writing that encourage skepticism towards psychiatric assessment, diagnosis, and treatment (see for example, M. White, 2007; M. White & Epston, 1990). Although I came to this placement with some background in these approaches, the practice of such skepticism was a direct challenge to my experience prior to this placement as part of a psychiatric research team in which all of our interventions involved attention to particular psychiatric diagnoses. Work in the Community Agency also differed from my current work as a crisis intervention worker because, in the counselling role I was learning, the focus was on eliciting families' preferred stories as opposed to typifying these stories through a diagnostic process. I understand the difference between these two ways of working to be reflections of these institutions' contrasting professional cultures.

Arthur and Russell-Mayhew (2010) describe the necessity of understanding different professional cultural worlds because professionals from these worlds increasingly collaborate with each other. In particular, these authors highlight the supervisory relationship as a space to learn about different professional cultures and roles. My supervisor at the Community Agency had extensive background and training in narrative and postmodern approaches and demonstrated this particular counselling perspective. He would question the utility of diagnoses, and he taught me to question the notion that merely assigning a diagnosis such as ADHD or Depression contributed to the successful treatment of the clients we helped. In my supervision sessions, my supervisor and I would deconstruct the psychiatric diagnoses contained in the often-large client files alongside details about the families' struggles to secure basic needs in their lives.

My experience of these Community Agency supervision sessions was, at first, like trading hospital-based diagnostic lenses for community-based lenses focused on client expertise. Through these community-based lenses, I learned to focus on the exceptions to the problems that clients sought help with. My focus on exceptions included asking about clients' hopes for the future and working with them to elaborate on times when their lives had not been dominated by the problems for which they were seeking help (M.White & Epston, 1990) and to highlight these clients' preferred responses to these problems (Wade, 1997). When viewing clients' difficulties through these community-based lenses, I worked with clients to understand psychiatric problems as merely a collection of symptoms such as lack of sleep, low mood, and decreased appetite. To expand upon these views, I began to ask not only about symptoms of psychiatric conditions but also about times when clients responded in ways they were proud of or when they were free of their distressing thoughts and physical symptoms.

As I grew accustomed to this new view, I began to notice new angles of inquiry. I deepened my understanding of how to ask about families' preferences and the stories that shaped these preferences—stories of resilience in the face of challenges and of different ways of living that often existed outside of the hospital's problem-based focus on particular diagnoses and treatment plans. In comparison to my hospital-based experience, the work I learned in my community-based placement consisted of journeying alongside families.

This community-based work reflected the contrast between community-based and hospital-based (i.e., medicalized) (Wampold, 2013) environments that is described by Madsen and Gillespie (2014) as “walking and talking” versus “sitting and talking” practices. Community-

based service providers used walking and talking practices, including meeting in clients' school and home environments, to journey alongside their clients versus the more removed hospital-based sitting practices of diagnosing and treating clients. As my knowledge and experience of this "walking and talking" approach of collaborating with families using narrative and postmodern approaches deepened, I learned that although these approaches advocated collaboration with families, they said little about collaborating with service providers from different orientations or agencies. I noticed that, while hospital-based approaches often include delegating aspects of problems to other services to treat (Winters & Pumariga, 2007), community-based narrative and postmodern approaches focused on bringing clients' strengths forward but do not address how to translate this strength focus to working in collaboration with other service providers.

Developing collaborative relationships with other services providers was essential because a large part of counselling at the Community Agency involved helping service users secure services from schools, hospitals, and other community agencies. These efforts included reconciling different perspectives as different organizations and service providers shared the care of a particular client. Although I appreciated the tools of postmodern and narrative counselling approaches, deployed in the Community Agency and which allowed me to step outside of diagnoses and standardized treatments, I came to realize that part of collaborating with other service providers involved developing the ability to speak in the language of diagnoses as well as in the language of narratives. Thus, I began to see that I had to combine the many lenses I had at my disposal. Moreover, I learned that despite the fact that different agencies advocated particular paradigms of practice and ways of viewing client problems, the providers working within these agencies all tended to adopt a pragmatic orientation, which often drew on multiple perspectives and practices and provided for collaboration.

My practicum in the Community Agency taught me that the work of engaging hard-to-reach clients might include being skeptical about the prevailing focus on psychiatric diagnoses, which were, and remain, a central part of hospital-based work. My hospital-based work differs from my experience of work within the Community Agency Youth and Family Counselling team in terms of the formality of the respective environments and the varying time constraints of the assessments. This is the case despite the fact that the Community Agency also offers services that more closely resemble the short term work I do as a crisis intervention worker and because the Children's Hospital also offers more long-term services. These contrasting experiences of

significantly different social practices point to the existence of different professional cultures (Hall, 2005; Kleinman, 1978). I encountered further evidence of these differing professional cultures when seeking approval to do research with clients who accessed services shared between the Community Agency and the Children's Hospital.

### **Seeking Ethics Approval**

The research ethics process took approximately half of the three-year data collection process and involved three research ethics bodies: The Community Agency's Research Ethics Committee (REC), the Children's Hospital Research Ethics Board (REB), and the REB of my University. Because the REB of my University provided approval based on the advice of the other two agencies' research ethics bodies, I will focus on the feedback that I received from the Children's Hospital REB and the Community Agency's REC to illustrate further elements of their respective professional cultures.

The feedback provided by the research ethics bodies of the Children's Hospital and the Community Agency represented different foci, which I argue demonstrates differences in the cultures that guide the practices of the professionals working in these agencies. I include their respective feedback because it helps to demonstrate how both community- and hospital-based research ethics processes are embedded in larger socio-cultural trends (Christians, 2005; Guta, Nixon, & Wilson, 2013; Holland, 2007; Shaw, 2008). In building on this scholarship, I argue that the specific concerns of the research ethics bodies stem from fundamental ideas that these agencies hold in regards to their clients, and thereby reflect elements of each agency's respective professional cultures. In particular, I compare my experiences with each agency to illustrate elements of each discrete professional culture following Stanley's (2006) description of how professions are defined both by their functions and by their interactions with other professions.

I made my ethics submissions to the Children's Hospital, the Community Agency and my home university's research ethics bodies before learning that the Children's Hospital REB must approve all such proposals first because the other research ethics bodies deferred to its REB as the authority on research with children. The initial approval process at the Children's Hospital REB took a number of months, and involved the submission of a number of forms and a long waiting period.

While I awaited the Children's Hospital's REB response, the Community Agency's REC expressed concerns with what they saw as the intrusiveness in my initial research design, because I proposed video recording an initial assessment session with new-to-treatment families.

After meeting in-person with their REC, they expressed concerns that videotaping initial interviews with families had the “potential to adversely affect client services by interfering with [the agency’s] early engagement process” and would, therefore, be “at odds with [their] professional responsibility to ensure the best possible outcomes for their clients” (written correspondence, December 6, 2012). Following this correspondence, I received feedback from the Children’s Hospital REB that requested further clarification regarding my training to assess suicidal and homicidal ideation, asked questions regarding recruitment, and gave advice regarding the simplification of the language in the consent forms and on the storage of confidential materials. Unlike the Community Agency’s REC, the Children’s Hospital REB only communicated through a representative and formal letters and did not request a face-to-face meeting.

Congruent with my descriptions of working in these agencies, the feedback provided and the procedures used by the Children’s Hospital REB and the Community Agency REC illustrate the differences between their professional cultures. These differences included the Community Agency’s REC meeting with me in-person and the concerns they expressed regarding the potential of my research design to cause harm, focusing specifically on the potential for clients to be dissuaded from accessing their services. In comparison, the Children’s Hospital’s REB did not meet with me in person and expressed concerns only about avoiding immediate harm such as addressing child protection concerns and asking about my ability to conduct a risk assessment. This approach resembled the Emergency Room focus I discussed above where there is a focus on immediate resolution of potential problems and immediate decisions according to pre-determined standards (i.e., the REB focusing on pre-established standards such as legislation and the evidence based risk assessments conducted in the Emergency Department). While the ethical concerns raised do not present a complete picture of the concerns of each agency, they do demonstrate different approaches to the concern of avoiding harm to clients, and what might constitute this harm. Because professions are recognizable not only in their definitions, but also in how their concerns compare to those of other professions (B.Davis & Sumara, 1997; Klein, 1996), it is useful to investigate and to compare the responses of these two research ethics bodies.

The Children’s Hospital REB was most concerned with researchers avoiding immediate harm to service users. Although the Community Agency was also concerned about immediate harm, their REC extended their definition of harm to include the possibility of causing clients to

disengage from services. While both research ethics bodies evaluated the same proposal, only the Community Agency commented on preventing clients from disengaging from their services. It therefore appears that the Community Agency prioritizes engagement, as shown by their foci on longer-term services and on-going engagement in counselling processes with clients to a different extent than was the case for the Children's Hospital REB, where the focus was on immediate risk reduction.

Overall, my experiences with the Children's Hospital and the Community Agency brought me into contact with different views on client engagement and preventing harm; I understood these different views as resulting from two contrasting professional cultures that, increasingly, interact with one another. The contrasting clinical environments and research ethics bodies' feedback of the Children's Hospital and the Community Agency provided evidence of these contrasting professional cultures. This evidence included a focus on risk reduction at the Children's Hospital, a medically oriented clinical environment, that was in contrast with the Community Agency's focus on more long-term client engagement. In this latter case, interactions were undertaken within a less formal environment, fostered by understanding the circumstances of families' lives and reinforcing these families' expertise. My work experiences in the Children's Hospital, and the Community Agency, as well as my interactions with these agencies' research ethics bodies, provided two contrasting contexts within which young people and their families experience mental health care in River City.

Stage I of my research sought to understand interagency collaboration from the perspectives of young people and their families who had experience of care across these two contexts over a number of months. As I explained in Chapter IV, I gathered young people and their families' experiences through focus groups and individual interviews and I present these stories organized around initial themes. These initial themes reflect the exploratory nature of these focus group and individual interviews. The results of the Stage I focus groups and individual interviews, combined with my experiences of the organizations under study, set the stage for my more in-depth exploration of families' experiences of continuity of care in Stage II (see Chapter VI), and for the combination of families' and service providers' responses to the presentations of my findings on interagency collaboration and continuity of care in Stage III (see Chapter VII).

### **Initial Focus Groups/Interviews**

To learn about families' experience of interagency collaboration, I consulted with three young people and five of their parents, all of whom had experienced at least six months of care shared between the Community Agency and the Children's Hospital. These consultations consisted of a focus group with three mothers, an interview with a mother and father, a focus group involving two young people, and a telephone interview with one additional young person. Parental focus group participants included: Olga,<sup>13</sup> whose son, Dimitri, participated in a later individual telephone interview; Karen, whose son, Jonah, participated in the youth focus group; and Diane, whose daughter, Nicole, was ultimately unable to participate. I facilitated the parent focus group and the youth focus group with two research assistants, who took notes during the group session. I interviewed parents, Joanne and Mark, whose daughter, Laura, participated in the youth focus group with Jonah, on their own, because they were unable to attend the parent focus group. To give a brief synopsis of these young people and their families' paths into collaborative mental health services:

- Dimitri had been identified in elementary school as struggling with ADHD and was followed by the Children's Hospital and the Community Agency until his 18<sup>th</sup> birthday;
- Jonah had been hospitalized at the Children's Hospital several times after numerous visits to the Children's Hospital emergency department and was subsequently involved with the Substance Use Counselling Agency, the Community Agency and the Mental Health Hospital;
- Nicole had been followed by the Children's Hospital, the Community Agency and the Substance Use Counselling Agency and was re-engaging in outpatient treatment with the Children's Hospital; and,
- Laura had initially been referred by a private psychologist to the Children's Hospital's outpatient services and, a number of years after finishing these services, was admitted to the Children's Hospital's inpatient unit for a number of months before being discharged to the care of a Behavioural Treatment Agency, while being followed by a Children's Hospital Psychiatrist and a counsellor at the Community Agency.

---

<sup>13</sup> All names are pseudonyms. I offered families the option to provide their own pseudonyms.

These young people and their families thus had a number of years of experience with interagency care in River City, and in the interviews described above, added substantial detail to my experiences of mental health services in River City. I organized the results of these interviews into categories to which I assigned codes and then grouped these codes into themes, representing fundamental meanings of the experience under investigation—in this case collaborative care—in the contexts that these meanings were discussed. I identified five thematic categories. They are: 1. Meanings of psychiatric diagnoses; 2. Meanings of psychosocial treatment, 3. Parents working without a map, 4. Parents connecting the pieces of care and 5. Evidence of collaboration (see Appendix F for a list of themes, corresponding codes and quotations). I will explain the themes below supported with verbatim quotes from transcripts of focus group and individual interviews..

### **Meanings of Psychiatric Diagnosis**

The Children's Hospital and the Community Agency, as described in Chapter IV, have worked to establish collaborative pathways to treatment with the ideal of a diagnosis being given by the Children's Hospital or a family physician leading to on-going treatment by the Community Agency or other community based agencies. However, rather than viewing the diagnosis as part of interagency collaborative care, parent participants viewed the diagnosis conducted by the Children's Hospital as the beginning of a treatment plan that may well involve other services (and that in their experience of collaboration between various services was often disorganized). Youth, on the other hand, viewed the diagnosis as being primarily related to the identification of appropriate medications and separate from other subsequent care.

Parents tended to describe diagnosis and triage as central to ensuring a subsequent successful treatment plan. Diane said: *"I think the inefficiency in the system is because of the lack of proper triage and assessment [of a mental health diagnosis] as early as possible when somebody is struggling."* The parents viewed this initial step (diagnosis) as critical to ensuring that their children then could be set on an appropriate treatment plan. Another mother in the parent focus group, Karen added:

*There are so many more people coming forward with mental health issues that the supply is not keeping up with the demand . . . There will always be this constant need for service time and I don't know what the answer is but... "I think more efficiency [of services] and like you [referring to Diane] say, proper diagnosis [and] triage."*

Karen and Diane's hopes for proper diagnosis and triage was echoed by Olga, who described her son Dimitri's diagnosis of ADHD and subsequent treatment as setting the path for treatment: *"It was a relief, you know, that it was just ADHD . . . because then I could [focus on] the right [organization, the Children's Hospital]"*. Diane summed up the parents' sense of the importance of the diagnosis providing the basis for subsequent treatment in her comment: *"It just strikes me though that if you have a clear diagnosis.... If you have a clear diagnosis and you have a clear place you need to go."*

However, instead of a clear treatment path resulting from a diagnosis, parents Diane, Karen, Joanne and Mark went on to describe that in reality diagnoses and associated treatment decisions were often made in isolation, which resulted in inconsistency between service providers. As Diane described her impression of her daughter Nicole's treatment: *"I don't really believe that we've had enough consistency in [Nicole's] care and treatment to really understand what truly her challenges are, and what is her mental health ailment."*

In this description, it appears that Diane felt that consistency amongst workers describing Nicole's mental health ailment would help with addressing the challenges Diane's daughter Nicole faced. Diane described her understanding of the origins of this inconsistency in the following way:

*There is reluctance in the mental health field to diagnose children and teenagers. . . [Nicole] had assessments and [clinicians] identified social anxiety issues and depression issues, but we have never actually had a diagnosis from a psychologist, psychiatrist, family doctor, or anybody.*

In contrast to her hopes for proper diagnosis and treatment as described above, Diane and her daughter experienced inconsistent treatment offerings by different service providers across different agencies and individual service providers (such as family doctors and private psychologists) who provided impressions of Nicole's condition, but no diagnosis. Diane attributed this to a reluctance by service providers to assign her daughter Nicole a mental health diagnosis. Thus, for Diane, a diagnosis indicated an answer to the question of which treatments would be most efficacious. From Diane's perspective, the reluctance of mental health professionals to provide a clear diagnosis for her daughter resulted in a lack of consistent treatment.

Somewhat contradicting Diane's hopes that a clear diagnosis would result in consistent treatment, Karen described watching her son Jonah's treatment by different agencies: *"We've*

*been through different agencies. So we've had different assessments. And they've come out with a little bit of a different angle. But the depression is consistent."* However, Karen did not feel that a consistent diagnosis of depression by multiple service providers resulted in consistent treatments, as she said: *"You've got your depression diagnosis, but [mental health professionals] have no idea how to treat it. They don't know. You don't have the scan like we have for a cancer and everything. So it's all guesswork."*

Both Diane and Karen, in their hopes for improved intervention and their current experiences of their children's mental health treatment, expressed their wish for a clear diagnosis and triage resulting in proper treatment for their children. In both cases, they described situations where various professionals made isolated assessments of their children and where those diagnoses or lack thereof, resulted in inconsistent treatment responses. From their experience, these inconsistent assessments appeared to occur in isolation from one another and resulted in a lack of proper treatment for their children.

Mark and Joanne described a positive outcome of contradictory diagnoses from two different organizations—the Children's Hospital and a community based Behavioral Treatment Agency. Although Mark and Joanne also reported inconsistencies between these two agencies, they were pleased that what they saw as an initial misdiagnosis was eventually corrected by a Behavioral Treatment Agency psychiatrist. As Mark described:

*[The Behavioural Treatment Agency psychiatrist] spent an hour or an hour and a half with Laura and said, basically, to us that she's pretty non-communicative, but this is what I think. He was bang on the diagnosis in that amount of time and for 5 or 6 months before that these other group of [Children's Hospital] professionals were all just all over the place.*

From the parents' perspectives, rather than interagency collaboration, the diagnostic process was conducted by separate service providers in isolation from each other, precluding any form of collaboration, or treatment plan shared between service providers from different agencies.

Like the parents I interviewed, the young people I spoke with viewed their diagnosis in isolation from any subsequent treatment. The youth described their diagnoses as corresponding to particular symptoms and to the prescription of medication to alleviate these symptoms. For example, Dimitri in an individual telephone interview described his understanding of his diagnosis of ADHD in the following way:

*To be honest, I believe ADHD is just a way somebody is born. Like, the way school is set up, we have to be sitting down, and we have to be listening all day, every day, pretty much. And, with my body, I can't sit down, and I need different ways to learn.*

Dimitri understood the ADHD diagnosis as a description of a particular problem he experienced—namely his difficulties with focusing and his struggles at school. For Dimitri, his diagnosis was a description of symptoms that posed difficulties with societal expectations (i.e., sitting and focusing in school). He understood that Children's Hospital service providers saw medication as the solution to these ADHD symptoms:

*I found that [Children's Hospital staff] were always trying to get me on some sort of medication. That medication can always solve it. You know like they weren't trying to find different ways. It was just like, [describing statements by treatment staff] "Oh this medication can help that, this medication can help that."*

Dimitri's experience of service providers' responses to his difficulties was to recommend medications—possibly a function of the Children's Hospital's predominant focus on biomedical explanations. Dimitri understood these medications as being offered as the only solution to problems associated with ADHD as *"they weren't trying to find different ways."* Dimitri's recollections were of a response to his psychiatric symptoms that was not connected to other treatments he recalled receiving, something I will describe in later sections.

Jonah and Laura, who participated in the youth focus group, also talked about receiving diagnoses in isolation from other services. Unlike Dimitri though, while these youths saw diagnoses as accurate descriptions of their troubling thoughts and behaviours, they did not see the diagnoses they had been given as connected to helpful solutions to their difficulties. For example, in the following two exchanges, Jonah described his diagnoses of specific Anxiety and Depressive disorders and his understanding of his subsequent treatment:

Noah: *Do you think when people told you that you had depression, you were depressed?*

Jonah: *Yeah, even before that though.*

Noah: *Yeah, did it change anything when people told you that you had depression?*

Jonah: *No, I don't think so.*

Jonah later spoke about his diagnosis of a particular anxiety disorder in the following way:

Jonah: *I've read the descriptions of like [Particular Anxiety Disorder] and stuff. . . It's pretty accurate: I tend to like, have like flashbacks...and like dwell on the past and like trust issues.*

Noah: *When you learned about what people were calling the problem that you struggled with, did anything change after that?*

Jonah: *Uh... meds. . . Besides that, not really... I never really liked taking my meds. Especially, like anti-depressants 'cause I didn't really notice anything happening... But then again I do drugs and shit, so....*

Typical of Jonah's responses throughout the focus group, his descriptions of psychiatric diagnoses were brief. At the same time, like Dimitri, Jonah connected his diagnosis with medications. He also described medications as the response to his diagnoses and conveyed his understanding of his diagnosis in isolation from descriptions of collaborative care. Unlike Dimitri though, Jonah did not express the desire for other suggestions; instead he speculated that his drug use may interfere with his medications.

The other participant in the youth focus group, Laura, provided another example of diagnoses as labels applied to particular symptoms. Like both Jonah and Dimitri, Laura described her diagnoses being made in isolation from other service offerings. Unlike Jonah and Dimitri though, Laura was much less specific about the diagnoses she had been given. The following represented a typical exchange after Laura had given a number of evasive answers to my direct questions about diagnoses:

Noah: . . . *What was the thing that you were most concerned about?*

Laura: . . . *Kind of...kind of life in general....*

Laura focused on her objections to Children's Hospital inpatient staff assigning her many diagnoses. Unlike Jonah and Dimitri, Laura described her diagnoses as staff members' misinterpretations of her behaviours. As Laura put it:

*I didn't want to leave [the Children's Hospital inpatient psychiatric unit] that's why I got all my wacko diagnoses. I went a little coo coo—so that I could stay because I didn't want to go back home . . .*

As Laura described it, she saw the multiple diagnoses she was given as staff members' misinterpretations of her resistance to returning home. Laura later referred to when staff decided she no longer needed these medications: "*When they kind of like . . .took away some of [the medications] and discharged me from the Children's Hospital . . . I was okay; I guess I don't have any mental illness.*" Laura seemed to characterise her eventual discharge from the Children's Hospital's inpatient unit to the Behavioural Treatment Agency, as indicating that Children's Hospital staff did not think she had a mental illness.

Dimitri, Jonah and Laura each explained their diagnoses as being related to particular symptoms or a staff member's reactions to specific behaviours, like going "coo-coo" in Laura's example. They each understood their diagnoses to be in isolation from other service offerings. In comparison to the stories of their parents, these young people did not report multiple workers' responses or workers' attempts to work collaboratively on their care.

In addition, the stories of the parents interviewed in Stage I indicated that while they hoped that a clear diagnosis would lead to a defined treatment pathway, research participants described psychiatric diagnoses and psychosocial treatments as being offered in isolation from each other. When Stage I parents and youth spoke about engaging with multiple mental health services, they conveyed a sense, counter to descriptions of interagency collaboration within organized systems of care, of often being lost amongst the various services they were receiving. Parents and youth did not describe non-medical providers' contributions when asked about psychiatric diagnoses which leads me to the participants' experiences of psychosocial treatments.

### **Meanings of Psychosocial Treatment**

I was interested in how young people and their parents described the contributions of community-based agencies to the treatment of their mental health conditions—what I hoped would represent the under-researched area of community-hospital collaboration (Poland et al., 2005). However, when research participants spoke about psychosocial treatment, they described informal interventions conducted in parallel to those of the Children's Hospital rather than being understood as interagency collaboration.

Diane described the various services involved with her family to support her daughter, Nicole:

*We have [Substance Use Counselling Agency] people to help us with drug problems. We have had [Community Agency] to help us with crisis intervention. We've had [Children's Hospital] at the table at various times to help us with the mental health issues.*

Diane understood that each agency was involved for a separate purpose; which were not necessarily understood as being integrated. Rather, each agency provided a service in response to specific needs. Instead of an integrated system of collaborating service providers, Diane perceived her daughter Nicole's treatment as divided up based on specific problems and only the Children's Hospital responding to her daughter's "mental health issues". Diane's description of her experience of services was very different than what I had envisioned as a coordinated response to a mental health diagnosis.

Olga also described the services she and her son Dimitri received as separate from one another. As Olga described:

*So, [Children's Hospital] helped us. I really love everyone [in the ADHD clinic], it was really great and Dimitri really liked to go there and up until he was 17... And then we went for counselling to [Community Agency] just to you know, talk as well.*

For Olga, the ADHD clinic represented the central treatment for her son Dimitri, whereas the Community Agency was somewhere that she and Dimitri could go “to talk.” Dimitri also mentioned psychosocial treatment and his most salient memory was the location of this treatment. As he described in the following exchange:

*Dimitri: It was pretty much just like family issues. Like I would go there because I'd sometimes get in fights with my mom. Not like physical fights, like we'd just have disputes and like...kind of like a family doctor.*

*Noah: Was that [Family Doctor]?*

*Dimitri: No, no. [Community Agency worker] was a woman. She did it in her house I guess you could say. . . She was a certified social worker and she [offered counselling] at a housing unit.*

For Dimitri and his mother psychosocial treatment was less formal. It was where they went to talk, and the meetings took place in a housing unit. This was a notable observation, given my previous experience of the Community Agency as practicing in environments where client engagement was the priority. It is interesting that Dimitri, during his interview, did not mention other locations<sup>14</sup> but mentioned that the woman he saw with his mother was a “certified social worker” and worked in a “housing unit”. These statements were notable because Dimitri did not otherwise describe the locations of his treatment and the qualifications of his service providers. Combined with his mother Olga’s description of the Community Agency as a place “to talk,” this family described psychosocial treatment as being separate and notably informal compared to treatment at the Children's Hospital that they described as involving medication and a precise diagnosis.

The other Stage I young people and their parents described Community Agency workers as helping with case coordination and with organizing practical aspects of their care. For example, Karen gave a description of her son’s Community Agency worker’s attempts at

collaboration with both the Children's Hospital and the Mental Health Hospital that appeared largely one-sided:

*I think it was more [Community Agency] reaching out than the other way, [Children's Hospital] did try and reach out to and get a connection with [Community Agency], but I just get the sense that they're so busy at [Children's Hospital]. They will make the call but if you don't connect, they're on to the next thing. So, they don't have time. . . . I find and even now the [Community Agency worker] is reaching out to [Mental Health Hospital] and they're trying to organize wrap things so that everyone can figure out: what are you guys doing?*

Jonah also described his Community Agency worker as making efforts to organize his treatment:

Jonah: [Children's Hospital inpatient unit staff] *never really put a safety plan together and they were supposed to. So, that didn't really work out.*

Noah: *So that's something [Community Agency worker] has done?*

Jonah: [nodding] *uh-huh*

Noah: *Do you feel like [Community Agency worker] built on what people had done before or did she kind of throw out the book and start again?*

Jonah: *Built on. That's what most people do.*

Noah: *What was the most important thing she built on?*

Jonah: *Probably on my family issues...*

Jonah particularly highlighted safety planning and working on his “family issues”. When I later asked Jonah what his Community Agency worker did to help him he said: “*She monitors me and makes sure I don't attempt [suicide].*” In the example of Jonah and his mother Karen, it appeared that they perceived the Community Agency worker's psychosocial treatment as making connections and ensuring that interventions recommended by the Children's Hospital were put into practice. Stage I participants described the interventions of Community Agency workers as separate from and different to those of the Children's Hospital. Rather than experiencing explicit collaboration between the Children's Hospital and the Community Agency, Stage I participants described these agencies as working in parallel, or at most, that the Community Agency ensuring that the recommendations of the Children's Hospital were put into practice.

---

<sup>14</sup> For example, Dimitri did not specify where he had his appointments with or the qualifications of Children's

### Working Without a Map

Young people and their families described their involvement of multiple service providers and referrals from one agency to another—which could be interpreted as signs of interagency collaborative care (Boydell et al., 2009). Parents’ recollections of their experiences of collaborative care between different agencies involved many dead ends, repeated assessments and, as a result, parents acting to coordinate their children’s care. Participants described these experiences in the context of feeling lost within an array of mental health services—which I likened to working without a map. Research participants described multiple attempts to find connections to, and between, various service providers.

Diane described her frustrations in dealing with multiple agencies for her daughter, Nicole, and a lack of information sharing between agencies and attributed this problem to agencies being disconnected from one another.

*I think the problem is that there’s no consistency in sharing of information that, you know—one organization that knows about your kid isn’t being transferred over to another organization. So, you know, they’re starting from scratch, right?*

Diane expressed her frustration with having to repeat her daughter’s story multiple times. These disconnections demonstrated a lack of informational continuity between agencies where, instead of one agency continuing from where a previous agency left off, workers in different agencies were, as Diane described “*starting from scratch*”—a phenomenon that I inquired about further in Stage II.

Another parent in the focus group, Karen, also illustrated a concern with multiple, disconnected points of contact when she described watching her son Jonah having to speak to multiple service providers. She related her understanding of Jonah’s experience to those of other youth: “*These kids have issues talking to people and you have to talk to four or five different people and sign . . . forms for all of them.*” Karen later described an experience with a service provider at the Mental Health Hospital who Karen recalled saying: “*Well, I don’t feel like we’re making a connection, because [Jonah] only wants to stay 20 minutes.*” Karen speculated that this lost connection was “*because [Jonah has] told his story already.*” Karen concluded that this pattern of requiring Jonah to tell his story multiple times—a function of limited informational

continuity (which I describe further in later sections)—detracted from workers’ abilities to connect to her son.

The experiences that Karen and Diane described demonstrated these parents’ frustrations with multiple points of contact to get services for their children. From the parents’ perspective, little informational continuity existed between the agencies these parents encountered and, as Karen suggests: *“It would be better if there could just be one point of contact instead of here, here. And as a person receiving the care I couldn’t imagine having to talk to all of those people.”*

Another challenging aspect of parents’ seeking additional services had to do with having to make many phone calls to secure services for their children. Participants reported that they had to make multiple phone calls following a referral from one agency to another, and times when they were aware of one service provider not returning another service provider’s phone calls. In both cases, participants expressed frustration with the lack of information transferred from one organization to another, and described feeling that this lack of information transfer resulted in miscommunication or unclear expectations, resulting in parents feeling lost between mental health services.

In Olga’s case, what she understood to be a referral from the Children's Hospital to the Community Agency was challenging because she had to call the Community Agency persistently to access services, despite the referral from the Children's Hospital. As Olga described it: *“It was just uhh—the waiting period was painful like-- I had to call and call [the Community Agency] and [it resulted in] miscommunication even from them to us, and then they had to re-start the process.”*

Olga understood that the Children's Hospital and the Community Agency were connected when she and her son Dimitri were referred from one agency to the next. Unfortunately, Olga experienced limited continuity of care between these agencies when she had to call repeatedly and expressed her uncertainty about the purpose of her son’s referral from one agency to another.

Participants also described times when they were aware that service providers from different organizations did not return each other’s calls. For example, Mark and Joanne cited a key juncture in Laura’s transfer from the Children's Hospital to the community-based Behavioural Treatment Agency in the following exchange:

Noah: *and did you feel like [the Children's Hospital] and [the Behavioural Treatment Agency] communicated?*

Joanne: *no, they didn't. They didn't communicate.*

Mark: *He didn't get a call back.*

Joanne: *the psychiatrist at [the Behavioural Treatment Agency] could not get, he left voice messages [with the Children's Hospital] and could not get a call back. No, there was no communication at all.*

For Mark and Joanne, the lack of communication resulted in their feeling that they had to make a fresh start with staff at the Behavioural Treatment Agency.

Youth research participants also expressed frustration with lack of coordination among service providers. Jonah mentioned an example of his Community Agency worker being unable to contact someone from the child protection agency. As he said:

*[Community Agency worker was] trying to get a meeting with the social...or [Child Protection Agency] worker and ummm she like booked a time to meet her but I don't know, things never really came up to it. The person was supposed to give her a call back but the person never picked up, never tried calling...*

Jonah went on to talk about how his Community Agency worker asked him to repeat himself to make sure that this worker did not miss any information. He did not mention the Child Protection Agency worker again and it appeared this worker was no longer involved.

Participants reported that phone calls not being returned resulted in miscommunication, unclear expectations, and disconnections between agencies. This disconnection related mostly to information not being exchanged and therefore a lack of continuity of care from one agency to the next. Parents found themselves responsible for ensuring their children got the follow-up treatment and care that they were referred for which resulted in increasing frustrations for them and their children.

### **Parents Connecting the Pieces of Care**

Research participants in Stage I, however, did not feel that the River City mental health services they accessed were centrally organized. Instead parents frequently spoke about their efforts to connect the pieces of their children's care on their own. To navigate mental health services, parents understood that they needed access to their children's health records. Issues of access to these records are tied to both provincial legislation, because young people over twelve years of age (and their service providers) have the right to withhold non-life threatening information from parents (Ontario, Legislative Assembly, 2004), and to parental desire to know more about their children's care, especially when the youth appeared to be struggling.

Both Karen and Diane also described times when they felt that they were not given all the necessary information to connect the pieces of their children's care. These parents related these experiences to issues regarding consent, where youth are able to restrict their parents' access to their health information. For Diane and Karen, these rules regarding consent made their experiences of trying to connect care more difficult. Karen commented that she would have liked to have access to Jonah's information to be able to connect the pieces of his care. For example, Karen described her feelings with regards to helping her son navigate mental health and substance use treatment:

*Now it's the substance abuse and of course Jonah is 16 now. So [service providers] did a big assessment and we don't have access to all the results. So, I feel like I'm working blindly—I never feel like I'm getting the whole story—I feel that Jonah . . . tells certain people things and not others. Because he doesn't trust all [service providers] . . . You never know what you're going to deal with next, you're always kind of on pins and needles. But as far as care goes—I mean I find—I mean I count us as lucky because we're able to tap into several different things but it's fractured [referring to mental health services].*

Diane also described her feeling of being shut out of her daughter Nicole's treatment and concerned that because she wasn't able to access all of her daughter's information, she was not able to advocate for the proper services for Nicole:

*When [Nicole] had her issue in grade 8, we were recommended to get an assessment done at [the Children's Hospital], and we did get an assessment . . . and, at 14 [Nicole's age], we were not entitled to the report. Why did that psychiatrist pat us on the head and say, "Oh, you should probably go get some counselling"? Why didn't she send us to the [Children's Hospital Outpatient] clinic? Immediately? . . . And two years later finally—two and half years later we finally get her into [Children's Hospital clinic] where she should have been in grade 8.*

In both Karen and Diane's cases, they questioned the adequacy of systemic responses to their children's difficulties and both mothers shared their feelings that if they had access to information they could have helped organize their children's care in a more efficient manner.

Parents also described how, even when their children accessed care, they had to advocate strongly to ensure that communication and engagement occurred. These efforts at facilitating connections involved parents working to understand what they could reasonably expect from

different agencies and service providers. As Karen described when talking about Jonah's initial referral from the Children's Hospital to the Community Agency: *"Once we were [referred to the Community Agency] it was good... We did get handed off to a few counsellors before we landed with the person that we have now."* For Karen, a referral to the Community Agency from the Children's Hospital did not mean an instant service response, as Jonah worked with a number of counsellors before his current one. Diane also described her efforts to get the family doctor to consult with a Children's Hospital psychiatrist regarding her daughter's medication and how she struggled to keep her child engaged in Children's Hospital services when her daughter did not show up to an appointment:

*I showed up at the [Children's Hospital] appointment that [Nicole] was supposed to be at and pleaded my case and that this kid needs to be in here and I don't care what your assessment says. Here. Here's all the stuff that we're going through.*

For Diane and Karen, facilitating connections for their children was an important part of their children's engagement in services. This facilitation included multiple visits to mental health treatment agencies and sometimes confrontations. For example, Karen described her efforts to have Jonah admitted to the Children's Hospital to facilitate his longer-term inpatient treatment at the Mental Health hospital:

*I got very angry at [Children's Hospital] and you have to kind of stand your ground and tell them that you don't think [Jonah] is ready to leave yet...we were at the [Children's Hospital Emergency Department] many times before Jonah was let in [to inpatient treatment].*

Jonah corroborated his mother's view when he shared his experiences in the youth focus group: *"My parents are like 'make sure you say this...' it's so you can get to the [Mental Health Hospital]."* For youth under eighteen years of age, the only way to get to an acute inpatient unit at the Mental Health hospital is through the Children's Hospital. This reality meant that Karen and Jonah had to visit the Children's Hospital many times before Jonah was admitted. This was one example of the persistence necessary to engage in services, including: treatment from the Children's Hospital; referrals to the Community Agency; and, collaboration between a family doctor and the Children's Hospital.

### **Signs of Collaboration**

Research participants also spoke about times that they knew their service providers were collaborating and when they had input on these collaborative processes or witnessed service

providers speaking to each other. Parents and youth witnessed tangible examples of handover between workers from different organizations. For example, Joanne described her experience of a Community Agency worker being present at a behavioral treatment agency meeting regarding her daughter Laura: *“What [Behavioural Treatment Agency] did, which was fabulous, they started having [Community Agency Worker] come to the [case coordination] meetings.”*

Karen also spoke about the physical presence of a Community Agency Worker at meetings to facilitate communication between different services. As she said in reference to her son Jonah: *“At the [Adult Mental Health Hospital], when Jonah had his discharge, they invited [Community Agency worker] to come and she was part of the plan.”*

In these examples, workers being physically present showed family members that agencies were communicating.

Parents also related physical presence to breaking down communication barriers. In the case of Diane, referring to her daughter Nicole’s case, where a specific service, called wraparound, and offered by the Community Agency, enabled open communication between workers who were physically present on a regular basis, as Diane described: *“So I fought like a maniac to get wraparound because in wraparound a [Community Agency Worker] facilitated getting [all service providers] to the table – every four weeks.”*

Karen also mentioned Jonah’s Community Agency worker getting other service providers around the table when she said:

*So [Community Agency worker] has been really trying to reach out to Jonah and really trying to with the people around the table [different service providers] figure out who’s doing what because she recognizes that Jonah has been bounced around.*

Olga also spoke about how the Children's Hospital coordinated with her son Dimitri’s school to ensure that he was involved in extra circular activities. As she described:

*“The people at [Children's Hospital clinic] [connected] with the [high school counsellor] and they were helping Dimitri to get into skiing club. It was really good they helped us a lot.”*

In these descriptions, parents detail how key workers organized services in their young people’s lives in order to ensure that all service providers were working together. These actions resulted in key workers connecting with other workers in a child’s life or ensuring that the young person’s various service providers were all working together.

While parents described workers’ physical presence at meetings and coordination between workers to add and organize services, youth described feeling that workers were

collaborating when these workers already knew information from previous treatment interactions. For example, Dimitri spoke generally about the various service providers he was involved with and how he felt that they had carried information forward:

*Like I know that they have the accessibility but I didn't know that they actually talk to one another, like they would call up my other doctor and say, "yeah, Dimitri". I thought they just had a computer and just accessed everything I say, not everything I say, but like pretty much what has been written about me.*

For Dimitri, that his various service providers knew information about him led him to believe that a seamless process—something he likened to a central database behind the scenes occurred between his workers to share information. Jonah also spoke about being aware of his workers sharing information across agencies. For example, he described a scenario of handover between workers at the Children's Hospital and the Mental Health Hospital:

*I find [the Children's Hospital and the Mental Health Hospital] are pretty good actually because I overdosed like two weeks ago and I had an appointment at [Mental Health Hospital] with [Mental Health Hospital psychiatrist] and she already had the file and everything.*

In these two examples, youth describe witnessing their stories being carried forward with little effort on their part. For these youth, this indicated that the various service providers in their life were connected. For Jonah in particular, the fact that the Mental Health Hospital and the Children's Hospital shared information presented a contrast to his experiences of a lack of collaboration between the Children's Hospital and the Community Agency. As he described: “ [the Mental Health Hospital] and [the Children's Hospital] are pretty well connected. Besides that, [the Community Agency] and [the Children's Hospital] are not even close at all.”

Young people and their parents also cited a tangible sign of collaboration – consent forms. For example, Jonah described his satisfaction with the Mental Health Hospital's assessment:

*The [Mental Health Hospital] has the documents and everything and I got like an assessment done probably during like the summer and pretty much all I have to do is to sign a form and [ Community Agency worker] can get access to it. It's pretty good.*

Jonah further described how the consent process gave him control of his information:

*I was at [Children's Hospital] and [community worker] didn't get any information besides that I was like there... That's about it unless I sign that consent form. . . But before that she had no clue.*

Olga also reported that consent forms were an indication of collaboration between the Children's Hospital and the Community Agency.

These examples show how consent forms provided tangible evidence that service providers were collaborating. It is interesting to note that these procedures around consent, when keeping in mind Diane and Karen's wishes for more information as discussed above, had both negative and positive effects. As Karen and Diane described, sometimes when their children's consent was required, they felt they did not have adequate information to navigate multiple mental health services. These contrasting views regarding consent led me to inquire further about how young people and their parents navigated service providers' sharing information in Stage II.

### **Synthesis of Stage I Findings**

Overall, Stage I participants described their experiences of receiving various services from multiple organizations that were not explicitly connected to each other. These descriptions were different than what I expected participants to say when asked about collaboration between multiple agencies regarding a young person's psychiatric diagnosis. Instead of speaking about service providers collaborating as a result of a psychiatric diagnosis, participants described different meanings of diagnoses—parents described diagnoses as ways to organize care whereas youth described the diagnoses they received as labels for their troubling thoughts and behaviours for which they were offered medication. Research participants did not connect their diagnoses to the treatments offered by community based practitioners and described these practitioners' contributions as having to do with coordinating service providers, providing a place to work on family issues, or building upon recommendations made by hospital based providers.

Research participants' explanations resembled previous phenomenological writing regarding client experiences of psychiatric diagnoses, where clients report that they experience receiving a psychiatric diagnosis as making an invisible part of themselves visible, and that adolescents often prefer to describe their diagnoses in non-pathological terms (Hayne, 2003; Moses, 2009). These findings also present new avenues to expand upon previous studies of parents' emotional responses to their children's diagnosis (e.g., Moses, 2011). Stage I participants' recounting of their overall experiences made me realize that in order to capture

interagency collaboration in Stage II, I would need to focus on participants' overall stories of care instead of focusing on collaboration that was explicitly related to a psychiatric diagnosis.

Stage I research participants also spoke about parents' efforts of working without a map and connecting the pieces of care. These two themes related predominantly to parents' experiences of having to actively work to connect their children's service providers with one another. These experiences contrasted sharply with descriptions in the literature of collaborative care between family physicians and psychiatrists (Kates et al., 2011) and movements towards systems of care (Stroul & Blau, 2008) for children and youth, where services are offered on a spectrum from least to most restrictive in response to young people's needs. In general, it seemed that parent research participants in Stage I felt that they were the ones managing their children's care. These initial findings resemble larger investigations, where authors report that parents describe themselves as getting involved in their children's treatment including taking on roles such as case managers when they are not aware that connections between service providers exist (Heller & Solomon, 2005; Miller et al., 2009; Tobon et al., 2015). Parents' experiences of being lost between services in Stage I made me ask more about how parents saw themselves as coordinating care in Stage II.

Stage I parents and youth also spoke about times when they did recognize that service providers were collaborating. These times included when different service providers were physically present at multi-disciplinary meetings and when service providers already knew about past treatment. Stage I participants also cited consent forms as signifying a time when service providers intended to collaborate with each other. These findings resemble previous research where authors report that adolescent clients appreciate when important adults are included in treatment decisions (Iachini et al., 2015) and that parents report they are more trusting of service providers when they perceive these service providers as connected to each other (Widmark et al., 2013). These findings, in combination with parents' expressions of disappointment with disconnected services, informed a focus in Stage II on how young people and their parents described both entering care with service providers and their experiences of these providers sharing information. A useful concept to describe information sharing is informational continuity, a dimension of continuity of care (Haggerty et al., 2003). In situating these findings in my experiences with the Community Agency and the Children's Hospital, I began to see how parents and youth experienced the medicalized (Wampold, 2013) environment of the Children's Hospital. In addition, research participants' recollections of Community Agency service

providers picking up on recommendations of Children's Hospital staff members resembled descriptions of “walking and talking” (Madsen & Gillespie, 2014) services. In Stage II, I investigate some of the specific actions that research participants attribute to hospital- and community-based service providers to further explore the interactions between the professional cultures of the Community Agency and the Children's Hospital.

## CHAPTER VI: NEW-TO-TREATMENT FAMILIES' EXPERIENCES OF CONTINUITY OF CARE

In this chapter, I present findings from the Stage II interviews with young people and their families who were followed by the Community Agency over a three-month period during which they began a treatment relationship with a service provider/team from the Children's Hospital following a psychiatric diagnosis. Informed by the findings from Stage I of this research, I set out to investigate the following question: How do new-to-treatment families describe continuity of care between the various professionals who collaborate to provide mental health care for their children?

I first present Stage II families' experiences of entering care and their initial descriptions of the diagnoses for which they received treatment. To depict these experiences, I use family members' words to construct profiles that provide a context for my subsequent exploration of the families' stories of collaborative care. I then present a thematic analysis of Stage II interviews, using a dimension of the construct of continuity of care—informational continuity. I conclude this chapter by considering these themes in the context of the professional cultures of the Children's Hospital and the Community Agency (as described by Stage II participants). I then go on in Chapters VII and VIII to reflect on these cultures, and my own learning.

### Family Profiles

#### Family 1: Catherine and Dave

This single parent family consisted of a father (Dave) and his daughter (Catherine). Catherine also has a brother whom I did not meet. I met with this family on two occasions at an office in my home University campus. They appeared Caucasian and alluded to struggling financially. As Catherine described it: "*Unintentionally, my dad would stress me out with money stuff because—my dad had to pay for everything for me and my brother.*"

**Entry to mental health treatment.** Dave and Catherine described their entry into services between the Community Agency and the Children's Hospital in the following way:

Dave: *I just found out that morning [when the school called]. Catherine had self-harmed and attempted suicide and . . .*

Catherine: *And suicidal thoughts. . . I think it was a huge eye opener for [Dave when], he got a call from my school. Because one of my friends found out, then she told the teacher, and then the teacher told the principal, and then the principal went to him. . . I was afraid because I didn't know how he was going to react.*

Dave: *I was really concerned. I wasn't mad, I was extremely upset that I didn't catch it. We went to the [Children's Hospital], to the Emergency Department. . . . [We] just went in there, and they were talking to Catherine as well as me—separately at times—and determined that she didn't need to be admitted. . . . but we needed to get something going with counselling. [I felt] absolutely lost. Just trying to determine what was happening to my daughter and from [the] perspective of—I'm not going to say lack of treatment—but that's the only thing I can come up with.*

Catherine: *I didn't have anything for a really long time.*

Dave: *Yeah there was nothing happening forever and I was just like, “Okay, what do I do?” There was—I mean I know they gave out pamphlets—but when you're stressing out trying to look after your daughter and make sure she's not harming herself, or just trying to be supportive of her while you're still trying to work, there's no time to look at these papers. We also had . . . [the Child Protection Agency] come to our house as well. That was because when the school found out, they are required to notify [the Child Protection Agency] that there was self-harm. [Following the family's Emergency Department visit, the Children's Hospital staff] referred us to the Community Agency for emergency care. . . . [Then] I made the initial call to [the Community Agency], and we set up a meeting to come to our place to do initial assessment, the intake assessment.*

Catherine: *No, there was the crisis thing, the mobile crisis unit first . . . Our doctor knows that too, our family doctor, paediatrician, whatever . . . we go there like every second week. [Describes the pediatrician helping the family with] anything from [waiting lists] to medication.*

Dave: *Yeah, [the paediatrician] checks up on her and makes sure things are [pauses] kind of level, they're not going backwards or anything like that.*

Catherine: *Then [the Community Agency] temporary counsellors and stuff [for a number of months], then I had a transfer thing for a month, and then I started counselling with [the Community Agency counsellor].*

When I first met Catherine and Dave, they were waiting for a new counsellor from the Community Agency, and were starting with an outpatient team at the Children's hospital.

**Catherine's understanding of her diagnosis.** Catherine spoke about her understanding of her diagnoses of ADHD and Depression during the first interview:

*A few of my issues were school-related because I wasn't able to learn and stuff, because I couldn't concentrate, and so I would do bad in school, and then the teachers would make me feel worse about doing bad at school. I was diagnosed with depression, but not depression because something has to happen for it to be that bad and then after a few days 'til like a month it goes away. So it's not something that can be treated with medication. . . . It's not like degrading or upgrading [that her depression can't be treated with medication]. The opposite of degrading—whatever that word is. It's just saying that my problems aren't something that can be treated with medication necessarily. I kind of say it weird, but yeah, I'm kind of the kind of person—like if it can be treated without medication—try that route first, and then do medication. I'm not, like, anti-pharmacy, but if there's a way to treat it without putting things in your body that aren't supposed to be there, you should do that.*

Catherine and Dave approached the interviews having been through a number of service providers, starting at the Children's Hospital, after a number of Emergency Department visits and spending time on waiting lists. In comparison to the young people I interviewed in Stage I, Catherine described her diagnoses through symptoms for which she was getting help as opposed to be connected primarily to medication. As I will describe in regards to continuity of care later in this chapter, it is interesting to note that Catherine and Dave described many false starts in their treatment process following their initial visit to the Emergency Department.

### **Family 2: Elise and Nancy**

This single parent family consisted of a mother (Nancy) and her daughter (Elise). They also appeared Caucasian and alluded to struggling financially. For example, when describing her Community Agency counsellor, Elise said: "*She's helping us out with clothing, too, for me.*" I met with Elise and Nancy twice in their home, an apartment located on a busy urban street.

**Entry to mental health treatment.** Nancy was quite quiet through the interview so most of the journey described below is from Elise's perspective.

*I needed a counsellor, so I went into the walk-in [clinic] because I couldn't handle it. My school also told me that I needed to get some help—I tried getting a school counsellor, but they told me that I needed to go to a walk-in. My mom came with me, explained to them what happened and stuff, and so, yeah, she explained to them what happened. . . . [Describes that, previous to her current counsellor], I had another counsellor at the Community Agency, but . . . she was more of a drawing counsellor, so I*

*had to draw out my emotions. Then, I didn't really like her. It wasn't really my thing, even though I love drawing. Like I love it, but it wasn't really my thing to draw out my emotions. So, then I got, I hooked up with [her current Community Agency counsellor] and, at the time, I didn't like her. I don't know. She just, at the time, I just did not really like her, but then we sort of—but then I started to get attached to her, like I grew up knowing her, like a good three years of my life. Yeah, she's awesome.*

*We have a family doctor [for] about a year—a year and-a-half. It's still kind of just us because [the Children's Hospital is] just helping us out—just like with trying to figure out what's wrong with me, 'cause the minute I find out what's wrong with me, I'll be happy. I just want to know what's wrong with me so that I can kind of avoid the [describes things that trigger her negative feelings (triggers)]. I still don't know what's wrong with me, and certain things trigger me, and I don't know what's wrong, so it's sort of all confusing. I want to figure out what's—want to figure out what's wrong with me. I want to figure out what I have and what I don't have. Because with the last two assessments that I got [at the Community Agency], I didn't agree with them, but with this assessment, hopefully, I agree with it.*

**Elise's understanding of her diagnosis.** Elise also described her understanding of her diagnoses when I asked her about what she was most concerned about and she responded:

*My mental state. Because I believe I have borderline personality disorder. Borderline personality disorder is—the main thing is you have trouble keeping friends. It's easy to make them, but you have trouble keeping them. Same thing with family and relationships. Even my mom knows I'm excellent at making friends. I'm a very open person. I'm very friendly, sometimes, if you don't get on my bad side. But I'm very good at making friends, but I can't keep [them], because I'll get overly clingy and that's probably borderline personality disorder. . . .*

*I don't think I have ADHD; I think I have ADD. ADD is attention deficit disorder. It's where you have trouble concentrating; the littlest thing will sidetrack you and that's how I am. But everyone thinks I have ADHD, but it's been all the sugar and caffeine I drink, that's what I think it is.*

*Even the family doctor, the family doctor, because I first walked into her—to the clinic, the night before I searched up borderline personality disorder 'cause it said on the TV, and I searched it up, and then symptoms came up a lot—like there's 30 or something,*

*maybe 35. So you know what? I'm going to go talk to the doctor about it. So I went to the doctor, and before I even brought it up, she said, "We think you have borderline personality disorder. That's why . . . like, we're going to refer you to [the Children's Hospital]." So I'm like, "No; I came to talk about that, that's a little weird." That was scary at first, because I didn't expect anyone else to think, like, the same thing that I do. So it was like, "What? You actually agree with me? I thought I was going bonkers; what?" But when you said that, I was like "Alright, alright." I was referred to [the Children's Hospital] and with this assessment—if it shows that I have borderline personality disorder you need specific medication for—plus borderline personality disorder, plus [with borderline personality disorder], you can get an eating disorder, depression, anxiety, panic disorder—everything that I already have.*

In comparison to Dave and Catherine's story, Elise appeared to be quite interested in getting a diagnosis to explain all her difficulties. In Elise's case, she appeared to emphasize the diagnosis in terms of getting a correct label and resultant appropriate treatment. For Elise and Nancy, the journey through the system was also prompted by the school's recommendation, but resulted in a path that did not initially involve the Children's Hospital's Emergency Department.

### **Family 3: Pakhi, Kiran, and Raju.**<sup>15</sup>

Pakhi, her mother, Kiran, and her father, Raju, are two-parent family who described themselves as first generation immigrants from a South Asian country. Pakhi also has a younger brother, Deb, whom I met briefly, but who did not participate in the interviews. Unlike the two previously discussed single-parent families, who struggled financially, this family appeared to have more means<sup>16</sup>. I met with Pakhi and her family in their suburban home for both interviews.

**Entry to mental health treatment.** Pakhi and her parents described their journey together:

*Pakhi: I think it was close to the end of the day. I think on the day that [the school counsellor] called my mom; I'm not sure if it was on the same day, but I think a few days later, that [the school counsellor] says that they should— they should take me to the hospital. [Then the family] went to the emergency room and then the doctor.*

*Raju: Yeah, yeah. I remember we went to the emergency and came back. She was not*

<sup>15</sup> This family selected their own pseudonyms.

<sup>16</sup> I have included these families' demographic characteristics because these characteristics (e.g., access to means) appeared to affect their access to service providers.

*admitted that time.*

Pakhi: *They said that if it gets worse I should come back and that—they asked a lot of questions—and then they told me to talk to people.*

Kiran: *So then, when I come home, then, me and my husband [describes making an appointment to see a psychologist who they knew of previously because of their son's previous treatment for a learning disability]. Then Pakhi started seeing [the psychologist] weekly for about a year. We thought things were going to be okay.*

Raju: *She was not on medication at that time.*

Kiran: [describes that after a year, Pakhi's condition was] *getting worse, worse, worse, counselling did not help at that time. Then [the psychologist] says that: "I think she needs some kind of medication so you need to talk to your family physician."*

Raju: [The family physician] *was increasing the dose every time, we go back. . .*

Pakhi: *Then, after Christmas break, I started going back to school again, and then it started to get worse. Then, the doctor said that I need to take pills instead of the liquid.*

Kiran: *Then, I was at work one day—I got call from the school that [Pakhi had overdosed on medication], and then we had to go to emergency. . .*

Raju: *At that point, she was admitted.*

Kiran: [Describes that when Pakhi was admitted, the parents talked to the Children's Hospital social worker, who asked about the family's finances] *because we are paying so much money out of our pocket;*

Raju: *insurance only covered, like, a thousand dollars. Like, twice a month is, like, two hundred, three-hundred-dollar session. [Describes the social worker telling the family about the Community Agency and that their services are free.] So I said, "Yeah, of course. For sure we can take that service." So then they are, yeah then [describes signing consent forms] and then, I don't remember, they actually it's big time it takes but it's okay, all the procedures taking some time. So then they said public counseling we can get, I said "Okay then until we get that counseling we continue with [the psychologist]." Then we finally get those kind of stuff. After we get that counseling we stopped [counselling with the psychologist].*

Pakhi: *After that, there was a [community nurse] who came to my school, and she would talk to me.*

Kiran: *Yeah, she came to school, and as well as [the Community Agency], but at that*

*time they did not give us counselling right away, but they said, “You guys can call us if you need help.”*

Pakhi: *They gave me a short-term [counsellor]. . . then, four months later, I connected with a long-term [Community Agency counsellor] and [Children’s Hospital psychiatrist]*

**Pakhi and Kiran’s understanding of her diagnosis.** Pakhi and Kiran also worked together to describe Pakhi’s diagnosis. To begin, Pakhi responded to my question of what her service providers were helping her with by saying: *“so that I don’t hurt myself.”* When I asked Pakhi what her difficulties were called, she responded: *“they call it depression.”* When I asked if she thought this was the best description of her difficulties, Pakhi responded by saying *“there was a doctor saying it.”* Kiran indicated that she and Raju agreed with what Pakhi was saying by reiterating: *“that she’s hurting herself, like same experience.”* Kiran continued by describing the evolution of her experience of Pakhi receiving treatment:

*She was telling me before that like, “I don’t like to go to school, I am kind of different.” Something like she was being bullied . . . That’s why I was scared that if I doubt her concern— it might be worse or something like that. . . I don’t know, at that time we are not . . . aware of this part, that she was hurting herself—So actually I am thankful to Pakhi, because then everybody’s involved with it, then [describes her relief that Pakhi was “diagnosed”].*

In their three stories, each youth and their family experienced different entries into care and responses to their diagnosis. All three families sought mental health services following their school’s recommendation. Following these recommendations, two families accessed services through the Children’s Hospital Emergency Department and one through the Community Agency’s walk-in clinic. The stories of these families reflect more complex patterns of service use than those described in large-scale studies looking at young people’s access to mental health services, such as Farmer et al. (2003), who report that young people initially accessing school services were less likely to access further services. The complex service paths described by Stage II research participants are closer to those service paths that Reid et al. (2011) report where families access many services concurrently when seeking mental health services. All families also involved their family physician/pediatrician in their care process, which appears congruent with Davidson and Manion’s (1996) finding that family physicians/pediatricians remain important in mental health care journeys. These families’ stories run counter to parents’ descriptions in Stage I, where parents questioned the utility of family physicians.

Catherine, Elise, Pakhi, and their families all faced different stressors and had different treatment histories, but shared the common experience of receiving care shared by the Community Agency's youth and family counselling and the Children's Hospital's outpatient teams. In comparison to the youth and families described in Chapter V, Catherine, Elise, Pakhi, and their families were in the beginning phases of receiving care from multiple agencies. In addition, none of the young people interviewed for Stage II were involved in substance use treatment, nor had they received treatment from the Mental Health Hospital.

In comparison to the Stage I findings, where parents described diagnoses as a part of their experience of getting treatment for their children, and youth described diagnoses as involving medication, the youth in Stage II predominantly described their diagnoses as holding the potential to make sense of experiences that distressed them. For Catherine, these experiences were her school difficulties and reactivity—for which she was given diagnoses of ADHD and Depression. Elise initially described seeking a diagnosis of Borderline Personality Disorder to explain her difficulties with friends and multiple struggles, something that she believed could be resolved with proper medication. Finally, Pakhi described her struggles as being called “depression,” because a doctor had described them this way.

When compared to Stage I participants' experiences of diagnoses as isolated, picked up inconsistently by different workers and associated with the prescription of medication, Stage II participants' descriptions of diagnoses presented a more heterogeneous picture. Young people and their parents in Stage II also described more direct connections between different service providers than did the Stage I participants. In particular, these families described being referred from school to hospital-based services. In addition, Stage I participants appeared to identify multiple entries to treatment whereas Stage II families, possibly due to their new-to-treatment status, refinements to the research questions, or because of improvements to the system, describe a more straightforward process of engaging in treatment.

### **Investigating Informational Continuity**

To further explore Stage II families' experiences of interagency collaboration I use a particular dimension of the construct of continuity of care, informational continuity. According to Tobon et al. (2014), informational continuity is service providers' concurrent use of information about prior events and social contexts to tailor care directly to the individual service user. To investigate this individual tailoring of care over time, I chose to conduct interviews at both the beginning and the end of a three-month period. As I described in Stage I, young people

and their parents spoke about noticing when their service providers were able to act upon information from previous providers as a positive indication of collaboration. Further, Stage I families identified gaps in information sharing as a key factor in their experiencing services as disconnected. In Stage II therefore, I wanted to more closely examine how families characterized collaboration between service providers.

In the section that follows, I present Stage II participants' descriptions of their experiences, sorted thematically and divided between initial and 3-month follow-up interviews, with particular attention to the dimension of informational continuity.

### **First Interviews**

In my initial interviews with Stage II families, young people and their parents described how they had come to receive treatment from the Community Agency and the Children's Hospital. As I depict in the families' profiles above, these processes of engagement took different paths, although they shared a common beginning in school staff noticing a problem and recommending professional help. From asking about how Stage II young people and their parents saw themselves as involved in the process of treatment, two notable findings emerged (Please see Appendix G for themes, codes and corresponding quotes for Stage II):

- Young people and their families often described initial connections between service providers but did not necessarily describe sustained efforts; and,
- Young people and their parents took active roles in making the mental health service system work for them regardless of the degree of connections between service providers.

**Initial connections.** Many of the stories Stage II families shared in their initial interviews, when seen from a perspective of informational continuity, involved providers "getting on the same page," or establishing initial connections between services. For example, during their first interview, Catherine and Dave described being about to begin with a new Community Agency counsellor in tandem with beginning to receive services from the Children's Hospital because their case had come to the top of the Children's Hospital trauma service's waitlist. For this family, the involvement of many service providers appeared to feel overwhelming. As Dave described it: *"It's either you struggle, struggle, struggle, and then you start getting help, and then all of a sudden, it's just like, all the doors open up."* From Dave's perspective, the long waiting time without services for Catherine left them feeling that they were starting over again when multiple services finally became available. From the family's

perspective, there was no continuity of care or information. Dave conveyed that he was surprised by the sudden service offerings and that it appeared these services were offered based on when they were available as opposed to when the family most needed them.

Elise's mother, Nancy described a very clear process of service providers tailoring service offerings to her and Elise's present circumstances. For example, in the first interview, when asked about a recent psychiatric assessment she and Elise attended at the Children's Hospital, Nancy described the Children's Hospital's communication with Elise's Community Agency counsellor: "*They wanted to know what [the Community Agency counsellor] was doing with her and everything—building on [Elise's previous treatment].*"

In these examples, families described two opposite experiences of new service offerings. Dave speaks to a lack of informational continuity after he and Catherine had waited for services for a number of months. In contrast, Nancy described her experience of the Children's Hospital "*building on*" previous treatment in the Community Agency reflecting informational continuity. In particular, she highlighted how Children's Hospital staff members had asked for permission to speak to their service providers and had made attempts to find out what had been done already. Both Nancy and Dave's families had gone through multiple services to arrive at the point when they were accessing Children's Hospital services. It is interesting to note that, while both families were offered new services, one family, Dave and Catherine, felt overwhelmed by these service offerings whereas Elise and Nancy viewed the addition of services as "*building on*" what had come before.

From a youth perspective, providers sharing information with each other was also important. For example, Pakhi described a specific example of service providers facilitating information sharing when she spoke about her discharge from the Children's Hospital's inpatient unit: "*We had a meeting before they told me that I could get out of the hospital. There was a community nurse there and there was someone from the Community Agency.*" Pakhi's experience of service providers sharing information was based on their physical presence together in a room as she was moving from one service to another, reassuring her that these service providers were communicating.

Dave's experience of feeling lost and confused both before and after "*all the doors opened up*" resembled Boydell et al.'s (2006) report that families in their research described mental health services as resembling a "tangled web" (p. 187). In contrast, Nancy and Pakhi's experiences of specific instances of information sharing resonate with findings from Miller et al.

(2009) and Tobon et al. (2015), who report that service users' satisfaction with services is significantly enhanced when they are aware of the nature of communications taking place between their service providers. Stage II respondents demonstrated that their level of satisfaction was somewhat related to their awareness of communication between service providers. In particular Dave's description highlighted the importance of information transfer being visible to families. His story suggests that the sharing of information between providers alone may be insufficient, if families remain unaware of that sharing.

Overall, family members identified three elements of interagency collaboration that affected their experience of informational continuity through their initial connections with service providers: lack of informational continuity due to long wait times before services became available; visible informational continuity when all service providers were present at key meetings; and, when service providers explicitly built on the actions of previous service providers.

**Roles in making the treatment work.** A common finding of researchers looking at client experiences of interagency collaboration and informational continuity is that parents take responsibility for facilitating communication when they believe that the communication between service providers is lacking (Miller et al., 2009; Tobon et al., 2015). In Stage I, witnessing disconnections between services led to parents working to facilitate their children's transitions between services. In Stage II, families described specific examples of managing young people's treatment by making sure their service providers were communicating.

Pakhi described believing that her Community Agency counsellor and her Children's Hospital psychiatrist were communicating by saying: "*Well, I talked to all of them and I got the same response.*" It later emerged in the interview that Pakhi's mother, Kiran had worked to ensure this communication, when I asked her:

Noah: *So, did you kind of feel like you made [Children's Hospital psychiatrist] and [Community Agency counsellor] collaborate?*

Kiran: *Yeah, I asked them. . . I first asked [the Community Agency counsellor] "Are you able to do that?" So, she said, "Yes, we can do that [communicate between counsellor and psychiatrist]." She asked [Children's Hospital psychiatrist], so she said, "Okay."*

The extra efforts Kiran went through to ensure communication between the two service providers may have been because this family, citing their South Asian cultural background and recent immigrant status, reported less understanding of mental health treatment than other

families. These differences from the other families I interviewed may relate to unspoken rules or discourses that are more apparent given the family's different cultural background. For Kiran, Pakhi, and Raju it appeared that having a consistent message regarding Pakhi's condition was extremely important. Kiran later tried to articulate this understanding: *"What I understand they're saying that this is kind of a—not a disease, I am not saying that—not regular kind of disease, diabetes or something like that, you give them medication and right away it's gone."*

Kiran went on to explain that it was quite difficult to understand how to respond to Pakhi's needs, because the parents were unfamiliar with North American understandings of both mental health and regular adolescent development. Raju and Kiran described feeling torn between their traditional ways of raising their daughter, as sanctioned by their community, and what professionals were telling them. Both Raju and Kiran described several times that the consistent messages from Pakhi's treatment team helped address their confusion. In this case, it appeared that due to the assertiveness of Kiran and the acuity of Pakhi's difficulties, the family's service providers not only focused on sharing information with the family and each other, but also on tailoring this information to the family's social context. This is in keeping with Waibel et al.'s (2012) finding that when service providers are consistent, it improves the ability of service users and service providers to work together.

Catherine and Dave also gave an example of consistency between service providers when they cited how some of their service providers connected with each other and how these times of connection actually served to illuminate times when they felt service providers were disconnected. In the following examples, Catherine and Dave were speaking about their efforts to provide continuity between treatments and the contrasts between their efforts and the efforts of their service providers. Catherine spoke about how she recognized that her pediatrician and her Community Agency counsellor communicated: *"[The Community Agency counsellor] was like, '[The pediatrician] told me blah blah blah' [and] 'Oh, what happened last week that like whatever?' And I'm like, 'Whoa, how did you know about that?'"* Catherine reported that she knew that the Children's Hospital *"would send the reports from the Emergency Department to [the pediatrician],"* which led her to believe that her pediatrician was the central figure who was managing her care. To Catherine this connection was very important, and it contributed to her trusting her pediatrician. However, Catherine cited a sharp contrast between visits to her pediatrician and visits to the Children's Hospital Emergency Department, where she and Dave tried to access immediate help between visits to service providers, thus attempting to provide

their own continuity of care, however, as Catherine described, these efforts often left she and her father feeling that service providers were disconnected: *“It’s almost like going to [the Children’s Hospital Emergency Department] is a punishment then ’cause they waste so much time just going over everything again. It’s like, ‘Aren’t these written down somewhere?’”*

For Catherine, it appears that service providers sharing with her that they had knowledge of her background story was comforting, unlike what she described as: *“punishment, just going over everything again.”* Catherine’s observation resembles the results of previous research on both collaboration and continuity of care, where young people and their families described having to repeat their stories as a key contributor to their perception of a lack of continuity (Haggerty et al., 2013; Tobon et al., 2015; Widmark et al., 2013).

Elise and Nancy provided two concrete examples of feeling like their service providers were sharing information and as a consequence feeling that their service providers were on the same page. For them, signing a consent form represented a clear connection between workers and agencies. When the Community Agency counsellor facilitated the purchase of a *“safety deposit box”* at the suggestion of the Children’s Hospital staff, it showed them that service providers were working collaboratively towards a similar goal—Elise’s safety.

In the first instance, Elise described how signing a consent form let her know that her Community Agency counsellor and the Children’s Hospital staff were communicating with each other and her school:

*Because we had to sign a consent form from the [Children’s Hospital], to talk to my school and [ the Community Agency counsellor], and we had to talk to—we had to sign some before, I don’t remember—all I know is that we had to sign some consent forms.*

In a similar fashion to Stage I young people and their families, it appeared that for Elise, being asked to sign a consent form gave her the sense that her service providers would be communicating with each other. While Elise did not give specific examples of the results of this communication, it appeared she was aware of her service providers talking and like Stage I participants, being asked to sign a consent form made her aware of this process.

Nancy and Elise also provided a specific example of how their Community Agency counsellor was able to build on the recommendations from the Children’s Hospital. According to Nancy, the Children’s Hospital *“gave me some ideas on trying to help her”* including *“a safe deposit box to keep her medication in.”* The safety deposit box demonstrated informational continuity, because the Community Agency counsellor helped this family to follow-up on the

Children's Hospital inpatient unit's suggestion to purchase a safety deposit box by helping the family secure funding for it. Nancy explained that: [the Community Agency counsellor] "*gave me a card . . . a Walmart gift card. So, I went out and bought it.*"

In the first interviews, all three families described how service providers contributed to making collaborative treatment work. They also highlight the efforts made by parents to facilitate service providers' collaboration. These efforts included specific actions that parents took (e.g., Kiran's intervention) to avoid feeling that they had to become their child's case manager, a situation that Tobon et al. (2015) demonstrate is particularly deleterious to families' trust in service providers. As Stage II participants described, service providers coordinating their efforts resulted in young people and their parents feeling that they were receiving helpful and connected interventions. Young people and their families highlighted actions such as building on suggestions from other service providers, giving practical resources to put care recommendations into place, and supporting families and providing them with tools that allowed Stage II families to use their care most effectively. In comparison to Stage I families' experiences, these families appeared more engaged in care and moved beyond descriptions of their accessing services to sharing their impressions of work resulting from the relationships between service providers. This might be explained in part by the immediacy of the experience to the Stage II participants; however, it is apparent that in contrast to the experiences of Stage I families, Stage II families are reporting explicit occurrences of inter-professional communication and collaboration.

### **Three-Month Follow-Up Interviews**

Following my initial interviews, I had hoped to gain a sense of how each Stage II family's collaborative care relationship had evolved over time because this evolution over time is a key aspect of the construct of continuity of care (Haggerty et al., 2003). In the follow-up interviews, 3 months after the initial interviews, I asked more specific questions about families' perceptions of the connections between the Children's Hospital and the Community Agency, including asking about changes during the intervening three months in the context of these families' evolving mental health treatment. In their follow-up interviews, families described their processes of continuing to engage in collaborative services between the Community Agency and the Children's Hospital. Tracking the evolution of new-to-treatment families' services was also a key aspect of my research design that I retained through the modifications to this design (see Appendix A). The three families I interviewed in Stage II provided three very different examples of this evolution that included: re-starting services; a period of crisis; and, an example of smooth

connections between service providers. I explored these families' very different on-going experiences of informational continuity within interagency collaborative care by asking them more about their attempts to find direction and effectively manage their care. From asking Stage II young people and their parents about their evolving experiences of collaborative care, three notable findings emerged (see Appendix G for themes, codes and corresponding quotes for Stage II):

- Young people and their families described instances of poor information transfer as contributing to needless detours in their treatment.;
- Young people and their parents also recalled polarized experiences of either service providers communicating effectively between each-other and these research participants feeling left to manage their care on their own, and;
- Young people described making choices about who could access their information, this made information transfer less of a straightforward process.

**Finding direction.** While all participants cited examples of communication between service providers, both parents and youth felt that instances of poor information transfer had caused needless detours in their pursuit of treatment. These experiences were similar to Karen's and Jonah's statements in Stage I concerning Jonah having to repeat himself many times and Diane's frustration with services "*working in silos.*" For example, Dave and Catherine's overall description of their encounters with services largely involved feeling lost throughout the process of a treatment path with many false starts. Their care felt directionless; as Dave described it: "*Not understanding fully what's going on, and then all of a sudden you have all these doctors trying to help you, but you don't know really what they're trying to get at, at times.*"

Dave described how he himself often felt lost in the information received from the different services he and Catherine used: "[I] *almost need to bring in one of those* [Dave pointed to my tape recorder], *so I can keep playing it back, until I can maybe understand everything.*" As Dave reported, he felt confused by the amount and variety of help he and Catherine were receiving once they got help. He described feeling overwhelmed with information, and speculated that having a tape recorder could help him put things together. To Dave this confusion seemed indicative of service providers not sharing information. For example, when asked, in their second interview, about communication between the Children's Hospital and the Community Agency, Dave and Catherine explained that they had the impression that these organizations were not connected in their case. As Dave described it: "*I wish they would be more*

*on even par. Like whenever something gets done at the Children's Hospital, that the counsellor or whoever was responsible for looking after or helping that child would get the same information."*

When I asked about the effects of this lack of informational continuity between the two providers, Catherine said, *"Having to re-talk about it again, we were probably missing some details and stuff like that."* For Catherine and Dave, their experience of a lack of information sharing between the Children's Hospital and the Community Agency, resulted in them feeling that they had to repeat similar information often, with the consequent risk of missing out details in the many repetitions. Dave and Catherine's experience resembles experiences of families as reported by O'Reilly et al. (2012) and Widmark and Sandahl (2013), who felt disengaged from treatment when they were unsure of what was happening next and/or when meetings and communications between service providers were not well-coordinated.

Elise also complained that lack of information sharing between the service providers led to her engaging in repeated interventions, which left her feeling disengaged:

*Oh, or it's like my [Children's Hospital group counsellor] and my [community nurse]. We both come up with safety plans, why don't they just share them together? Yeah, like me and the [community nurse], we came up—we did a safety plan and everything; why didn't [the nurse] call [the Community Agency counsellor] and tell her that?*

When I asked Elise what it was like when she felt her service providers were repeating themselves, she responded:

*I get down, but when they over-communicate with me, it's kind of like, "Okay I've heard this talk, like, twenty thousand times. You don't need to tell me—just get to the point, get to what, get to the end of it."*

While this repetition of safety planning may have been a function of professionals doing their due diligence, Elise experienced this as evidence that her service providers were not communicating.

Dave, Catherine and Elise felt lost when there was a lack of information communicated from one service provider to the other. In Dave and Catherine's case, there were so many people involved in Catherine's care that she and Dave felt they could not keep track of the information. Both Catherine and Elise reported having to repeat similar tasks again and again and the possibility that details might be missed when they told their stories multiple times. These experiences are reminiscent of Jonah's recollections of his frustration in Stage I, when he spoke

about being discharged from the Children's Hospital inpatient unit and having to repeat his story to the Community Agency counsellor, and to Diane's feeling that all the organizations helping her with Nicole were in their own silos and did not share information with each other.

The experiences that research participants described may be contributing factors to the patterns of service use that Reid et al. (2011) identify where families seek similar services from agencies concurrently. The experiences described by Stage I and II participants invoke Raingruber's (2003) claim that clients of collaborative care experience multiple mental health services like a broken puzzle with pieces shifting around in a big box. In other words, the families I interviewed in both Stages I and II described connections between services often being unclear, which led to frustration when the services seemed disorganized and connections were not apparent. In particular, both Catherine and Elise's experiences of having to re-explain and repeat themselves resembled frustrations expressed by other mental health service users when they felt that services were disconnected and reactive in nature (Haggerty et al., 2013; Jones et al., 2009). These accounts are also reminiscent of previous findings where families described themselves as having to manage children's mental health care (Tobon et al., 2015).

**Managing care.** Stage II respondents reported instances of very polarized experiences of connections between services in terms of management of care. Stage II families described experiences when service providers were communicating among themselves, and thus managing their care through ensuring informational continuity. At the same time, research participants also reported experiences of being left on their own to manage their own care with little communication and therefore limited informational continuity between services. These examples were not so much about finding direction, as described above, but more about young people and their parents having to put the pieces of interagency collaborative care together themselves.

For example, Elise had experienced a period of crisis, which resulted in a number of short admissions to the inpatient unit of the Children's Hospital, between her first and second Stage II interviews. She described feeling that, during her transition from the inpatient unit back to her school, all her service providers were on the same page. When I asked how Elise knew this, she responded: *"Because they give each other ideas about how to help me."* When I asked for more details about these ideas, Elise provided the following example: *"Me staying out of school for a bit. They all kind of agree to it."* This showed a way that service providers from the Children's Hospital and her school helped Elise transition from one environment to the other. In this example, Elise perceived that her service providers were connected, following a stay at

Children's Hospital inpatient unit because they all agreed on a similar plan.

While Elise provides a positive account of informational continuity, Catherine and Dave frequently returned to recollections of when they had been seeing their previous Community Agency counsellor and accessed the Children's Hospital's Emergency Department after Catherine engaged in self harm. The following description summarizes Dave and Catherine's experiences of this process: *"The problem is, whenever we go to the Children's Hospital because of stuff, because they don't know [about Catherine's previous visits] they don't know anything. I have to sit there and repeat my whole story again, and then they're like, 'Try this,' and I'm like, 'I've tried that before. I've been here multiple times'."* This highlights the lack of informational continuity even within the one service provider (Children's Hospital) where suggestions are repeated even though they have been previously tried and been found ineffectual.

Dave described his experience of the Children's Hospital Emergency department during his efforts to organize interagency collaborative care for Catherine in the following way:

*There's nothing there for the families or for the children, specifically for the children, but for the families to draw on. Like, they give out the literature, but half the time—I don't know about most parents, but with me—I didn't have time to read the paper.*

Dave is referring to informational pamphlets given out to families who visit the Emergency Department. This kind of information is intended to help families transition to more permanent services, an attempt to complement the short-term interventions offered in the emergency department. However, as Dave recalled, he felt that he *"didn't have time to read the paper;"* which rendered this attempt at providing informational continuity to be not very useful. Catherine also expressed her wish for more support while on the waiting list:

*I think [Children's Hospital] needs to have, like, a thing, like, if you're on a waiting list that's, like, a longer waiting list for anxiety or depression, or even like that, they should have bi-weekly classes for parents to be able to hold their children over—that's just me. Because I'm lucky to have a dad that kind of knew what to do from the start, after going to [Children's Hospital] two times. But like, I know a lot of kids that aren't that lucky.*

Catherine recommends access to, and follow-up with, mental health services as a way of ensuring continuity of treatment. Instead, Catherine came to rely on her father, Dave, to navigate the system; Dave became the informal case manager. Dave described his struggles during this time by saying, *"The first six to eight months, you might as well say, unless you're willing to fork out a lot of money and do it privately, there's not a lot of help for people that can't afford it."*

In contrast to Catherine's experience of a lack of informational continuity, Elise spoke about feeling that the Community Agency and the Children's Hospital had been communicating when she was hospitalized:

*When I was admitted [to the Children's Hospital], they would talk. They would go—they'd call [the Community Agency counsellor], let her know what's happening, and all that stuff. And when I was in the hospital, like, when I was admitted, I know they had called [the Community Agency counsellor] to let her know how I was doing and everything, and they kept her updated and stuff.*

Finally, Pakhi gave a very specific example of her service providers sharing information when they decided on changes to her treatment regime. In particular, Pakhi spoke about how her psychiatrist and Community Agency counsellor communicated:

*Then [the Children's Hospital psychiatrist] also said that [the Community Agency counsellor] called her to tell her about that. . . . It was good because then I have, like—then I don't really have to re-explain everything to every person, and I know that they know each other.*

In summary, Stage II participants experienced varying degrees of information continuity and the evidence above suggests that the lack of information continuity as reported by Catherine and Dave caused significant frustration. These findings confirm the work of Iachini et al. (2015), who argue that having a sense that service providers are sharing information makes young people and their families feel secure in their treatment relationships. Conversely, when services appear disconnected, parents take more of an active role as 'case managers' and at times act in ways more intrusive to the clinical process (Heller & Solomon, 2005), or actually attempt to manage treatment (Reid et al., 2011; Tobon et al., 2015). Evidence from the Stage II participants suggests that the more families experienced transparent communication between service providers, the more families reported feeling that their treatment was being managed by service providers in an integrated way.

At the same time, I learned from my interviews with Stage I participants that regardless of information continuity among service providers, some parents were concerned about the lack of communication between the providers and themselves. Parents in Stage I encountered difficulties in accessing information that they believed would have resulted in their being able to more effectively advocate for their children. I speculated in Stage I that these difficulties in access may be due to regulations related to confidentiality. However, in Stage II I learned that

young people did not always want everyone involved in their treatment and may make choices not to make certain information available to parents.

**Young people taking control of their information.** Informational continuity ideally involves service providers sharing information to promote service users' smooth transitions between agencies. However, as Tobon et al. (2015) describe, the situation where both service providers and parents are attempting to organize children's care presents a unique challenge for children's mental health care—where service systems empower young people to grant consent to access their information. At the same time, authors writing about informational continuity and collaboration between service providers claim that the flow of information between relevant service providers and important adults in young people's lives is the ideal state of affairs (Cohen et al., 2012; Iachini, Hock, Thomas, & Clone, 2015; Tobon, Reid, & Brown, 2015). Nevertheless, research participants in Stages I and II described examples where certain adults were excluded from accessing information by the young people. Elise, Catherine, and Pakhi all described instances when they made choices about who accessed their information. These findings, when combined with Stage I findings, where youth also did not always want their parents to access all their treatment information, indicate that informational continuity may be more complex than simply ensuring that youth information is shared with all professionals, family members, or other significant adults. Pakhi's description of her preference to allow certain service providers and not others access to her information reflected descriptions by other youth and demonstrate how young people took charge of their information:

*It's like, there was a reason why I put on the consent form that there were certain people that I wasn't okay with communicating. Like for example, there used to be a [community nurse] that came to my school after I was discharged from the hospital, and she was allowed—I said that my parents were allowed to tell things to her, but she wasn't allowed to share certain things with, like, [the Children's Hospital] or my parents or with [the Community Agency], and she said to a certain extent that is okay unless it is concerning my safety and stuff.*

For Pakhi, it was very important for her to control the ways in which her service providers contributed and collaborated about to her care. She recalled feeling quite overwhelmed, previously, when her care was largely determined by others. In this example, Pakhi describes a common experience of youth wanting to limit the people who have access to their information. This finding reinforces Freake et al.'s (2007) argument that adolescents'

perspectives are not sufficiently represented in the literature and Iachini et al.'s (2015) observation that youth want the people they see as important in their lives included in their treatment. Pakhi's concern regarding who had access to her information and what information was shared between various providers demonstrates how informational continuity is more complex than service providers simply sharing information but also involves young people being comfortable with this information being shared with all adults involved.

In addition, Pakhi appears to have felt that she had more ability to act intentionally and change her life circumstances, what authors refer to as *agency* (Bandura, 2006; Munford & Sanders, 2015; Tomanović, 2012), than Elsie and Catherine in her ability to choose who was involved with her care. Pakhi's experience resembles that of Jonah in Stage I where he felt that his ability to control information flow between agencies by signing a consent form allowed him to feel both that these different agencies were collaborating and that he was in control of his information. It is interesting to note that, while Pakhi's family was of an immigrant background, they appeared to be more affluent than the other two families I interviewed in Stage II.

These different perspectives, as I described in Chapter III, derive from the different cultural locations available to each participant. In Pakhi's case, she is part of an adolescent culture in addition to being part of a culture of young persons who receive mental health treatment. Pakhi also appears to have experienced herself as having more agency than others I interviewed in Stage II; this could be a function of her family's affluence relative to the other families I interviewed in Stage II. From these different cultural locations, Pakhi has a divergent priority from those of service providers regarding informational continuity—privacy and from others interviewed in Stage II—a sense that she was in control of her treatment. Pakhi's concern with privacy makes the question of informational continuity more than one of asking if providers are effectively sharing information between agencies, this information sharing is contingent on the comfort of service users. This further consideration is not as yet addressed in literature on informational continuity.

Overall, as these research participants shared, their experience of informational continuity within interagency collaboration consisted of connections between service providers being reinforced through the signing of consent forms, visible communication, and other service provider actions. Research participants also described when information continuity was not in place through missed connections and unpredictable service offerings, having to repeat their stories, and/or parents taking on the role of "managing" their services. The young people and

their parents shared these experiences in the context of seeking psychiatric diagnoses as explanations for their concerns, and seeking care from multiple service providers who were developing their own forms of interagency collaboration between the Community Agency and the Children's Hospital, often with the assistance of other service providers.

### **Professional Cultures**

As I describe previously, participants in this study relayed experiences that took place in the context of the professional cultures of the Community Agency and the Children's Hospital. In Chapter V, I characterize these two contexts as conceptualizing risk in terms of precise diagnoses and reduction of immediate risk (the Children's Hospital) versus an emphasis on families' stories and engagement in services in addition to reducing immediate risk (the Community Agency).

In Stage I, I found that young people and their parents said very little about relationships with service providers in the context of Interagency Collaborative Care, instead they focused on issues of access and service providers' actions that contributed to these respondents' trust or lack thereof of individual service providers. To elicit richer descriptions of Stage II research participants' experiences of service providers in the context of interacting professional cultures, I asked Stage II young people and their parents to describe how the Children's Hospital and the Community Agency were helping them (initial interviews). Building on my learning following Stage I and my increasing awareness of the professional cultures of the organizations implicated in this investigation, Stage II participants described more community oriented services (e.g., organizing treatment, securing resources) offered by the Community Agency. However, when describing the Children's Hospital, young people from both Stage I and II used particular language connected to an expectation of precise and conclusive treatment. Informed by my experiences in the organizations under study and my Stage I interviews, I followed up on my questions regarding professional cultures in my 3-month interviews by asking who was in charge of young people's care. The question of who is in charge of care also followed from my understanding that persons from medical environments (i.e., the Children's Hospital) are often ascribed greater status than their community-based counterparts (e.g., Madsen, 2009). Research participants' responses to these questions illustrated their different experience of the cultures of the Children's Hospital and the Community Agency, as well as how they saw themselves and other providers in the context of their treatment.

**Initial interviews: Community Agency and Children's Hospital.** Elise and Catherine had similar descriptions of differences between services offered by the Community Agency and

the Children's Hospital. For example, when I asked Elise about her Community Agency counsellor Elise said, *"She is helping me with—What's the word again? —my emotions, my feelings. And she's helping us out with clothing, too, for me."* I then asked Elise, *"What kind of stuff are you hoping [the Children's Hospital will] help you out with?"* Elsie replied: *"To figure out what's wrong with me."*

Similarly, when I asked Catherine about her expectations of the of the Community Agency and the Children's Hospital services, she described her hope that her new counsellor at the Community Agency would help her *"actually be able to, maybe, talk to my [non-custodial parent] about things. That would be nice."* Catherine had described a traumatic history with this parent during the interview, and she expressed her hope that the new Community Agency counsellor would help her open a dialogue with this parent. In comparison, Catherine said she hoped the Children's Hospital would *"just kind of help [her] understand what's actually going on."*

While it is a subtle difference, it is interesting to note that, like Elise's expectation that the Children's Hospital would *"figure out what's wrong"* it appears that Catherine also implies that the Children's Hospital will be more precise when she expects them to figure out *"what's actually going on."* These responses indicate a certain conclusiveness about the answers that young people expected from the Children's Hospital. When asked about their communication, Pakhi acknowledged that these people had different approaches: *"They sort of used different things, and then they talked about that kind of stuff."* In comparison to Elise and Catherine's descriptions, by saying *"different things"* it appeared Pakhi acknowledged that her Community Agency counsellor and her Children's Hospital psychiatrist took different approaches, but she did not expand on the nature of the differences. When considered in light of Stage 1 parents' descriptions of seeking diagnoses from the Children's Hospital, and my own experiences of working at the Children's Hospital focused on reducing risk and working in a language of diagnoses, these descriptions seem to reinforce the "sitting and talking" versus "walking and talking" distinction described by Madsen and Gillespie (2014). In this case, sitting and talking is associated with conclusive observations like *"what's really going on,"* which contrast sharply with securing clothes or improving communication with a previously estranged parent

**3-month follow-up: Who's in Charge?** At the 3-month follow-up interview, Catherine was between a number of Children's Hospital and Community Agency services, whereas Elise was in a swirling period of crisis where many service providers were involved in her care and,

relative to Catherine and Elise, Pakhi appeared to be moving steadily through treatment. Given these young people's very different care circumstances, it was interesting to note that both Catherine and Elise described professionals external to the Children's Hospital and the Community Agency as keeping their care together. As Catherine explained to me: *"It's kind of like, I don't know what it's called, with the two graphs, the big circles. . . [the Children's Hospital] is one of them and then [the Community Agency] is the other, and then me and my pediatrician are in the middle."* In other words, for Catherine, she and her pediatrician are at the intersection of the experience, working together to encourage the Children's Hospital and the Community Agency to collaborate.

Elise and Nancy also described people outside of the Children's Hospital and the Community Agency as organizing Elise's care. This mother and daughter disagreed, however; on who was the centre of this care arrangement. Although Elise began by saying, *"I find my guidance counsellor helps out a lot with school, and school's one of my biggest issues right now. And then my [Community Agency] counsellor helps out a lot with home and family issues,"* Her mother, Nancy, immediately added: *"And also I believe the family doctor . . . [because the family doctor] gives you the medication."* Elise disagreed with her mother about the family doctor, because: *"The thing is I don't need medication, if I have help I don't need the medication."* So, for Elise, the central people in her treatment were the people that helped her with the issues most at hand. For her and her mother, the various counsellors offered the most assistance. In this example, I wonder if Elsie described the walking and talking people as being most relevant to her treatment journey; whereas, she only peripherally acknowledged the medical sitting and talking (i.e., prescribing medication) people as an important part of treatment. Both Elise and Catherine's descriptions of the roles of their service providers differed from Pakhi's treatment process which appeared much more stable in comparison. Given this stability, it is interesting to note that Pakhi was less specific about differences between her psychiatrist and her Community Agency counsellor. During her 3-month, follow-up interview Pakhi reported a very collaborative relationship between her Community Agency counsellor and her Children's Hospital psychiatrist. Both Pakhi and her family reported that she regularly saw both her Community Agency counsellor and her Children's Hospital psychiatrist. Possibly as a consequence of this stability, Pakhi gave a description which appeared to imply that her service providers were effectively sharing information in a transparent way:

*I guess like if [the Children's Hospital psychiatrist] or [the Community Agency*

counsellor] *has something that they think ...should be changed or should be done, they would talk about it, and they would tell my parents and whoever else, and they would sort of decide together. I don't think it's really one person who's in charge. I think everyone has to work together and they have to think of the best solution, or—yeah, that's how I see it. I've never seen like one person be—like one person make the choice—one person to decide that this is how it's going to be done.*

In these three examples, young people noticed differences between their community- and hospital-based service providers that appeared supportive of Madsen and Gillespie's (2014) “walking and talking” versus “sitting and talking” distinction. In comparison to my interviews and findings in Stage I, it is worth noting that Stage II young people described Community Agency services supporting them in various areas of living (i.e., clothes, communication, relationships) versus their description of Children's Hospital Services providing specific answers. Participants' expectations of specific answers from the Children's Hospital also seemed to imply a recognition of expertise deployed by Children's Hospital staff that was not available to members of the Community Agency. In comparison to Stage I results, young people in Stage II, who were just entering services, pointed out differences in what the Children's Hospital and the Community Agency could offer. Stage II youth distinguished between the Community Agency and the Children's Hospital in their descriptions of what they expected from the two services. These expectations also appeared to relate to the degree that youth felt their services were organized.

### Summing Up

In this chapter, I reported the results of my interviews with new-to-treatment families regarding their experiences of continuity of care in the context of interagency collaboration for the treatment of a psychiatric diagnosis as they began treatment. These interviews were informed by my findings from Stage I, where I learned that experiences of successful interagency collaboration had less to do with collaborative care, and more with how service providers' specific actions contributed to, or took away from, participants' experiences of the treatment progress as they transitioned between agencies.

Stage I findings informed Stage II by helping me focus on new-to-treatment families' experiences of receiving a psychiatric diagnosis and how these diagnoses formed a context for their subsequent interagency collaborative mental health treatment. Building from the context of entering services and young people's understandings of their diagnoses, I focused on

informational continuity—or client experience of their service providers sharing information and then using this information in a clinically useful way. This focus enabled me to inquire into how young people and their families experienced their service providers sharing information and the effects of this information sharing on the degree to which services were coordinated.

In comparison to their Stage I counterparts, Stage II youth were much more active in their descriptions of their diagnoses and their hopes for, and understandings of, these diagnoses. Youth described diagnoses as making sense of troubling feelings and thoughts, as a sought-after label, as access to medication, and as a correct explanation offered by medical professionals. These families also described their entries into mental health services each beginning with crises at school subsequent to which they were filtered through acute services—the Children's Hospital Emergency Department in two cases and the Community Agency's walk-in clinic in a third.

All families in Stage II encountered many services as they became engaged in interagency collaborative treatment. Their initial descriptions of this engagement process involved a range of services from school counsellors and a psychologist to the inpatient unit of the Children's Hospital. All families in Stage II cited contact with a family physician to access services, an experience that differed from their Stage I counterparts. Stage II research participants were in the initial phases of experiencing interagency collaboration while Stage I research participants had experienced this collaboration for at least six months. As I learned in my interviews, the new-to-treatment families had more to say about how their providers communicated and their experiences of this communication than veteran families did.

In regards to informational continuity, Stage II families, in their initial interviews, described processes of getting their service providers on the same page. Compared to Stage I families, Stage II families described more aspects of service providers collaborating with each other. These descriptions included joint attendance at meetings and parents describing providers building on the efforts of others. This experience was juxtaposed with one family's experience of a long wait followed by being able to access many services at once. Parents in Stage II also offered more descriptions of how they managed their children's care by making explicit connections between service providers and describing how people outside of the collaboration between the Children's Hospital and the Community Agency (e.g., a pediatrician) supplemented continuity of care between the two agencies. One of the Stage II youth Catherine, described the extent to which a lack of informational continuity can be deleterious to one's experience when she described having to re-explain her story as "*a punishment.*" In comparison to their more

reserved counterparts in Stage I, Stage II youth described more aspects of their experiences of communication (or lack thereof) between agencies, such as signing consent forms, hearing about collaborative communication with their family physician, and observing a Community Agency counsellor picking up and putting into place recommendations made by the Children's Hospital. These practices of informational continuity left families in Stage II feeling supported by their interagency service providers in a way not shared by Stage I respondents, who appeared to focus more on access and the integration of their views.

In their 3-month follow-up interviews, Stage II young people and their parents described both ends of the spectrum: reports of either being lost and feeling overwhelmed by lack of information sharing between services; or, a smooth integration of service providers' views. Youth felt overwhelmed when they had to repeat the same procedures, and one parent felt that he could not keep track of the various recommendations he was given. In these interviews, young people and their parents also provided examples of experiencing smooth information exchanges when all of their service providers agreed on ways forward; families also made suggestions for supports that could support families who were waiting for services. Youth in Stage II cited examples of communication between service providers, and discussed not having to repeat their stories as an important benefit of this communication. It was of note that, although Stage I parents complained about not being able to access information about their child, youth in Stage II, even when they were very engaged in their treatment, did not want all of the adults involved to know everything.

In regards to experiences of the different professional cultures, Stage II youth described wanting conclusions from their Children's Hospital providers and wanting more practical help, such as improved communication and general help with, as described by Elise, her "*emotions and stuff*," from their community counsellors. Although one youth did not point out explicit differences, she did acknowledge that it was important to get her service providers on the same page, and she observed that they did initially display different perspectives.

The Stage II youth differed from parents and youth in Stage I, and from my experiences of the two agencies under investigation, by providing rich detail on their often-tumultuous processes of engaging with interagency collaboration in the context of a psychiatric diagnosis. Stage II young people and their families described their experiences of the slipperiness of building connections and making them work. These young people also described their

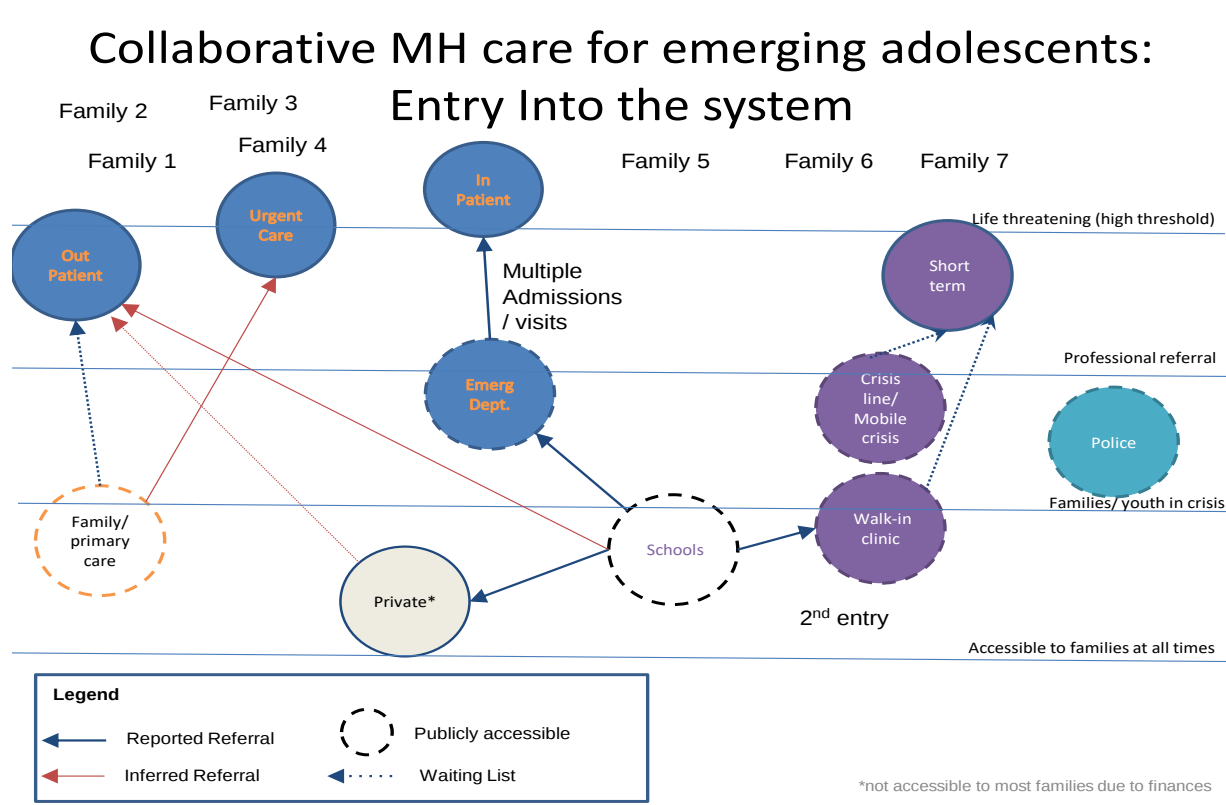
expectation of the Children's Hospital as offering conclusive answers unlike their expectation of the Community Agency offering ways to help them adapt to their present circumstances.

It is also interesting to note that these families described very different experiences of agency in regards to their travels between the Children's Hospital and the Community Agency. Where Elise and Nancy and Catherine and Dave all struggled to feel engaged in treatment processes at various points, Pakhi's family appeared to have an easier time of negotiating collaborative relationships between service providers from different organizations. It is noteworthy that Pakhi's family, while being of a different socio-cultural background than the other families I interviewed, was a more affluent two-parent family in contrast to the other single parent families in Stage II. In addition, it appeared that both Elise and Catherine accessed the mental health system through the intervention of physicians. This gateway appeared to facilitate further forward movement, more so than the interventions of non-physician professionals, and may hint at how families described the agency of different service providers relative to one another. I will explore this point further in my discussion of professional cultures in Chapters VII and VIII.

To present the stories of Stage I and II families, and offer some tentative conclusions regarding their impressions of interagency collaboration, I constructed two timelines that included all families' service journeys as well as a chart of families' points of view (see Appendix H). These timelines demonstrate the circuitous journeys of Stage I and II families. This chart of points of view (positions) shows different perspectives that families shared over the course of the interviews regarding collaboration between agencies. In Chapter VII, I will describe family and service provider responses to these diagrams, juxtaposed with my discussion of the results of the interviews, and the results of a study of families' views in River City that was recently conducted by staff at the Children's Hospital.

## **CHAPTER VII: STAGE III SERVICE PROVIDER REFLECTIONS**

In this chapter, I summarize the perspectives of two Children's Hospital-based teams, and one Community Agency-based team, in response to slides that I created to summarize the initial results of my interviews with the seven total Stage I and II families. I created three slides to summarize their treatment journeys and perspectives on interagency collaboration (see Figures 2, 3, and 4, below).



*Figure 2.* Stage I & II families' entries into mental health services. This slide represents how young people and their families described their entries into mental health services.

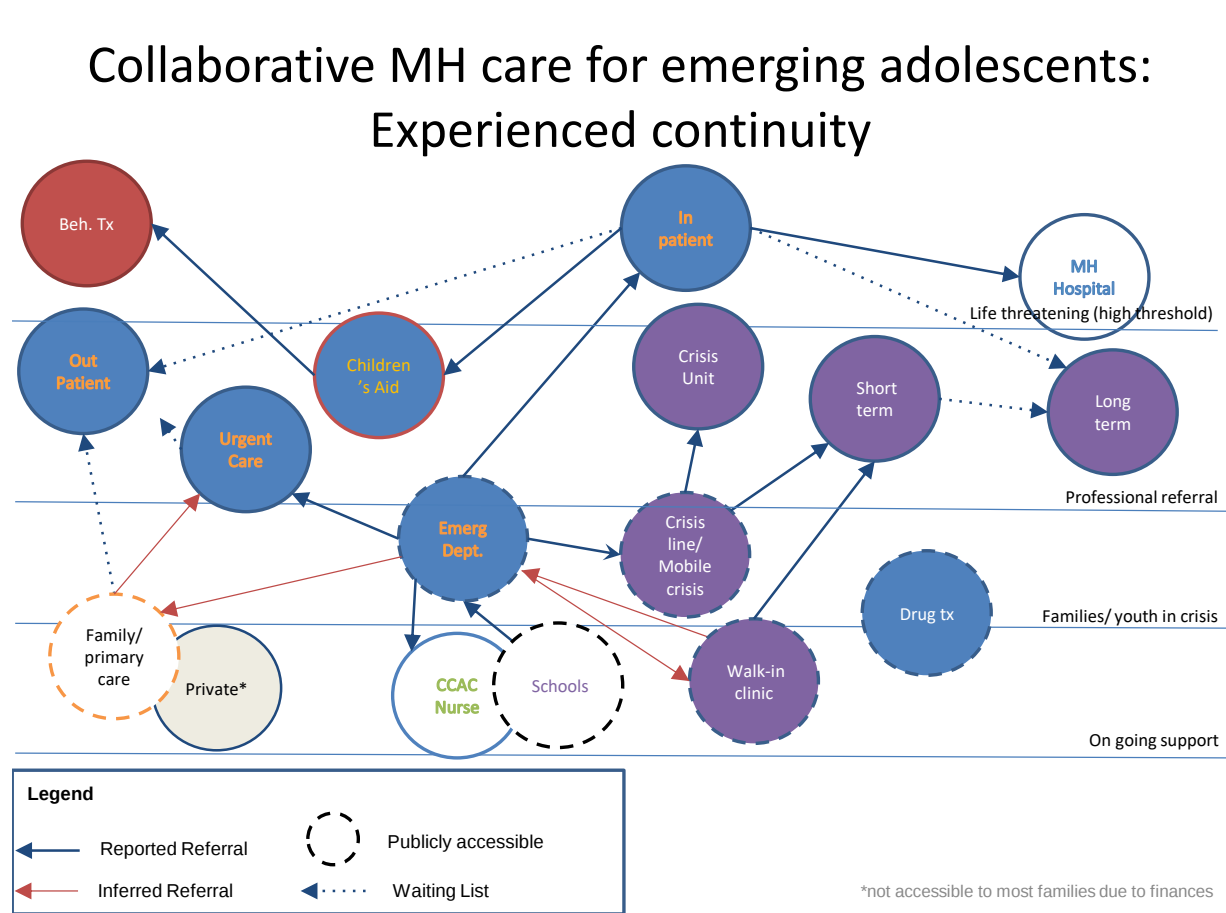
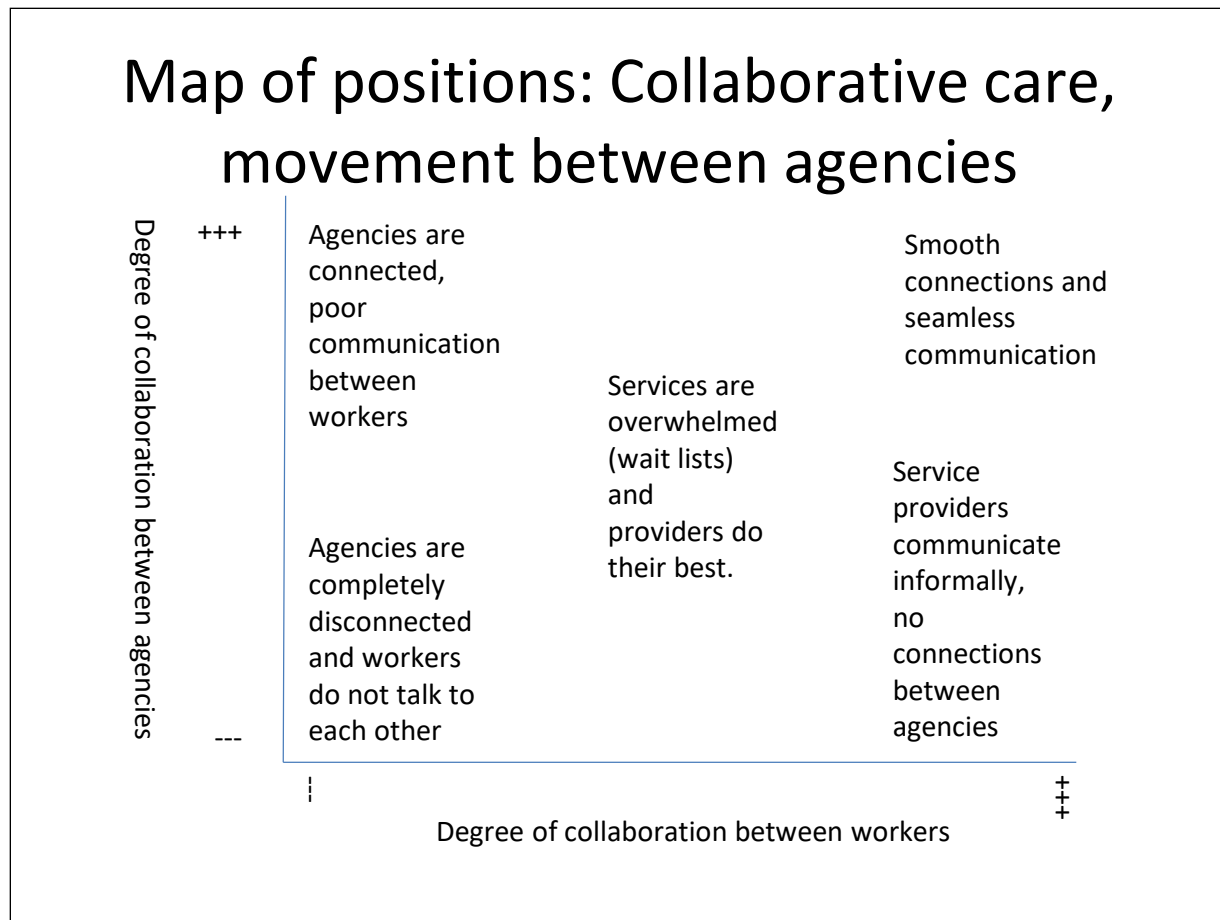


Figure 3. Stage I & II families' experiences of continuity of care. This slide represents how stage I & II families described information flow between service providers.



*Figure 4.* Discursive positions of families in Stages I & II. This slide illustrates the various perspectives Stages I & II young people and their families took on their overall experiences of collaborative care.

My presentation of these slides separately to service providers from two teams at the Children's Hospital and to a Community Agency team in Stage III constituted a chance to add a different lens to and elaborate upon my results from Stages I and II. These presentations and discussions in Stage III enabled me to co-construct (Morrow, 2005) my final results by integrating service provider reflections with my findings. In presenting the slides to the service providers I spoke about the youth and families' experiences of receiving psychiatric diagnoses and the resultant treatments. I shared my initial findings of families' experiences of interagency collaboration and how they sought connections and informational continuity in support of the management of their children's care.

**Service provider reflections on families' stories of seeking connections.** Service providers shared many thoughts on how difficult it is for families to feel that mental health services are connected. For example, a Children's Hospital-based worker on the ADHD team

said, *“The parents are faced with a system that is very fragmented, and it’s fragmented in ways that—it’s not planned out in ways that would be best for the patient; it’s pretty arbitrary.”*

Another expanded on their colleague’s thought by saying, *“[The mental health system is] difficult for [families] to understand and navigate; it’s a bit haphazard.”* This feeling of haphazardness was reinforced by a participant from the Mood and Anxiety team who, when referring to the maps presented, pointed out that *“there were way more circles than people.”* By “circles,” this respondent was referring to the fact that the maps showed more services (11 in Slide 1; 14 in Slide 2) than the number of families (7) whom I interviewed in Stage I & II.

Both hospital-and community-based respondents commented on the hopelessness that practitioners feel in regards to their difficulties making connections. For example, a Community Agency respondent described how they were not surprised at the illustration of *“the bouncing back [between services as] the family went there and went there and went there.”* A Children’s Hospital Mood and Anxiety team member also related the feeling of watching families bounce around the system: *“Most of the cases we don’t know where we stand as families keep bouncing back.”* Another Children’s Hospital Mood and Anxiety team member summarized many families’ journeys: *“They try this, and they try that, and they kind of fumble along until something happens, but they’re not sure what they’re getting or how they got there.”*

Service providers described circumstances that supported their efforts in seeking connections. They spoke about familiarity with other service providers as being key to interagency collaboration. For example, a community-based service provider said, *“Where collaborative care actually works is from workers who work [or have worked] in various settings.”* A member of the Children’s Hospital ADHD team concurred with this observation, saying, *“I have noticed that people prefer to call people they know, or you have the number at hand, or you know how they will react.”* Processes that worked involved knowing who to call, or service providers contacting other service providers who they know, either through working with them previously or through another case.

Service providers, much like the families in Stage I and II, described their experiences of interagency collaboration in a way similar to Raingruber’s (2003) box full of disconnected puzzle pieces. In families’ experiences, they moved between many services and identified collaboration between agencies only when it was explicitly absent or present. Families’ experiences reinforce Spencer et al.’s (2006) observation that resources such as service coordination are less prominent within current children’s mental health systems in that families

described themselves as the ones seeking to make the connections. These family experiences reinforce current findings that present children's mental health services as disconnected (Boydell et al., 2006; Davidson & Manion, 1996; Farmer et al., 2003; Offord, 1987). Service providers also described themselves as witnessing families bounce between services, and they speculated that families accessing multiple services were acting in crisis versus treatment mode. The service provider description of families "*fumbling along*" recalls Boydell et al.'s (2006) description of services as a "tangled web," and their reflection on families "*bouncing*" between services illustrates a particular version of Reid et al.'s (2011) observation that families sought multiple services concurrently. These findings show that families very easily feel that services are disconnected, and they may respond to that feeling by seeking additional services and taking increasingly active roles in managing their children's care.

**Service provider reflections on families managing care.** The construct of informational continuity was used to characterize how families experienced service providers sharing information and using information to shape treatment (Tobon et al., 2015). In Stage I and II, I found that families described informational continuity as being related to them being supported in managing their children's care (Figure 2 and 3).

Service providers described families trying to manage their own care, often by seeking out many services at the same time. As one member of the Children's Hospital's ADHD team said, "*One of the things that parents spend a ton of time doing is seeing 'what other services can I get?'*" A Community Agency counsellor reiterated this saying, "*Families, too, they're kind of fishing for services to avoid or to look at wait lists a little bit differently.*" Service providers shared stories of families contacting many different providers in an attempt to find the best service. These comments were offered in response to my presentation of results regarding families speaking about their frustration regarding being on waiting lists. A Community Agency team member gave a practical example of families trying to speed up services: "*I found that most families that go to the [emergency room] that are my clients, are ones on waiting lists.*"

Service providers described that, as a consequence of families seeking many services concurrently, family members became the *de facto* case managers in their children's treatments. Service providers spoke about their mixed experiences of families taking on this role. As one of the members of the Children's Hospital Mood and Anxiety team said, "*I find [that] because in our service there is a lack of continuity of care, [families] end up being their own case managers.*" Another team member added, "*Families understand that [they are the most*

important members of their care team], *but they are really burnt out, overwhelmed, or overloaded, and they've been through tragedy and difficulty. That's a lot to expect.*"

The difficulty of service providers managing care when families are accessing multiple services was emphasized by a member of the ADHD team who added, "*My experience is that we rely on the family to say 'I've just been to the walk-in clinic'.*" A number of comments were made about families having differing capacities to manage their children's care. For example, one participant from the Children's Hospital Mood and Anxiety team noted that the message to families that they are in charge can feel quite complicated. She speculated, "*I think families in distress can feel abandoned by the message that they are in charge.*" Many participants spoke about efforts within the system to support families taking charge of their own care. Participants stated that these efforts ranged from the establishment of system navigators to advertisements promoting families as important members of the care team. Service providers agreed that a family in charge of its own care was not a formally understood part of the present system and they questioned whether families needing to be a part of their own care team, was a result of a disorganized system.

In my exploration of young people and their families' experiences of informational continuity, or the use of information about prior events and social context to tailor care directly to the individual service user (Tobon et al., 2013), I learned that they described the sharing of information as impacting their management of the care process. These experiences of informational continuity were complex in that families spoke about the sharing of information between service providers primarily as it impacted on their abilities to use treatment. Some young people and their families described the absence of service providers sharing information as "*a punishment,*" leading to feelings of being overwhelmed and frustrated by having to repeat their stories.

Service providers reported that current mental health services give the, often frustrating, message to young people and their families that they are in charge of their treatment, which leads to families feeling lost in a system that appears disorganized. These findings demonstrate that significant work remains to be done in order to adequately respond to the recommendations of previous research and social policy documents that recommend services be client centred (e.g., Boydell et al., 2009; Gagné, 2005; D. White, 1992). Young people and their families appeared to be satisfied when service providers were explicitly connected, recalling findings that showed families to be more trusting when they experienced consistent information flow between workers

(Heller & Solomon, 2005). These findings also lend credence to the need to ensure consistent relationships over time between service providers and families and to pay particular attention to transitions. These actions relate to the dimensions of continuity of care referred to as relational and management continuity (Reid et al., 2002; Tobon et al., 2014), which I did not address explicitly in this study. These dimensions build upon families' descriptions of service providers integrating their perspectives and organizing their care in ways that bolstered young people and their families' abilities to adapt to their challenging circumstances or to needing to manage their care. The need for young people and their families to manage their care appears to be typical of the experiences of families and service providers whom I spoke to in River City. These disconnections and expectations illuminate the ways in which services interact with each other and with their clients, interactions I argue, are based on professional cultures.

### **Professional Cultures**

In this hermeneutic phenomenological study, I present my reporting of young people and their parents' experiences of treatment for a psychiatric diagnosis, their seeking of connections between service providers and managing their care as situated (Haraway, 1988) within the professional cultures of the Community Agency and the Children's Hospital. In Chapter V, I described my experiences of these cultures from three different viewpoints:

- My current job as a crisis intervention worker at the Children's Hospital;
- My previous experience as a placement student at the Community Agency, and;
- My experiences of seeking approval from the ethics bodies of the Children's Hospital and the Community Agency.

In so doing I reveal contrasting professional cultures that reflect the distinction Madsen and Gillespie (2014) make between *sitting and talking* and *walking and talking* practices. I described my experiences of the Children's Hospital as resembling a sitting and talking culture and my experience of the Community Agency as a walking and talking culture. In building on these initial observations, I report Stage I families' experiences as consisting of seeking answers from Children's Hospital staff and experiencing Community Agency staff members as focusing on organizing care. In my Stage II interviews, young people described Community Agency counsellors as being focused on practical aspects of their care (e.g., improving communication, securing material resources), while in comparison, they sought conclusive answers from the Children's Hospital. Findings from Stage I and II therefore, appeared to reinforce my

observation that the Community Agency focused mostly on engagement in on-going treatment; whereas, the Children's Hospital focused primarily on reducing risk.

**Service provider reflections on professional cultures.** In Stage III, participants spoke extensively about their experiences of distinctions between the professional cultures of the Children's Hospital and the Community Agency. For example, Mood and Anxiety team members described their experience of what they called “*brand recognition*.” As one member put it, “[Children’s Hospital] *is a brand that people trust*.” Another participant in this focus group said that numerous clients demanded services from the Children’s Hospital, “*because we’re the experts*.” These team members also made the distinction that the Children's Hospital Mood and Anxiety team provided assessments, and other organizations provided treatment. As one team member put it: “*Yeah, we assess a lot, here at [Children’s Hospital]. There are lots of opportunities to be assessed. Treatment, I think the perception is that, more often, [is delivered elsewhere]*.” Children's Hospital practitioners were not always comfortable with this perception, and some discussed themselves as working in tandem with organizations such as the Community Agency in providing treatment. One participant on the Children's Hospital ADHD team stated that families sought out his services instead of other, similarly qualified professionals “*because I work at [Children’s Hospital], they somehow think I’m better; I’m not*.” Community Agency practitioners were divided in their experiences of collaborating with the Children's Hospital across their professional cultures. On the one hand, one member of the Community Agency focus group said, “*My experience is when a family is seeing someone through [Children’s Hospital] outpatients, [service providers] never return my calls. . . . You get the idea of the level of respect [they have] for the work that I’m trying to do*.” On the other hand, when speaking about another service within the Children's Hospital, a Community Agency group member said, “*Certainly, [Children’s Hospital inpatient unit] is really good at working collaboratively*.” These providers described an evolving relationship between the two agencies that was enhanced when certain workers had experience in both agencies. As I described in Chapter I, the Children's Hospital and the Community Agency have been making more effort to collaborate in recent years. As one of the participants in the Community Agency focus group reflected, “*twenty years ago, truly no one was working together*.” Another participant added, in reference to a current initiative, “*You wouldn’t see a psychiatrist and a [Community Agency] worker doing [a therapeutic group] together*.”

There was also discussion of hospital-based services being potentially biased in favour of other hospital-based services over of community-based services. Community-based providers spoke of a lack of connection with some hospital-based staff due to an inability to reach these staff. These providers described how difficult it was to make interventions with families in support of other interventions, when both service providers and families experienced hospital-based staff as inaccessible. There also was acknowledgement that sometimes one professional would not return a different professional's calls. As one participant in the Mood and Anxiety team group said, *"I also think it's important to note that some professions will have more success [with collaboration] than others because of hierarchies."* This respondent cited particular examples of some professionals' calls being returned more frequently than others' and specified that it was less likely that a psychiatrist would take a call from a social worker than they would from another physician.

In the ADHD clinic group, a team member explained, *"I also think there's a hierarchical notion that you need to get to the top of the hierarchy, you need to see a psychiatrist. . . . I do think people want to get to the top of this hierarchy."* Group members also considered that there was a hierarchy to working at the Children's Hospital versus the Community Agency because medical professionals are seen by the general public as having a higher status. It was apparent from these professionals' reflections that Children's Hospital staff were seen by community members as experts whose services were in high demand, and Community Agency staff described having trouble connecting with Children's Hospital service providers. Children's Hospital staff acknowledged the existence of hierarchies and Community Agency providers described these hierarchies as changing slowly.

I considered my experiences of the Children's Hospital and the Community Agency, Stage I and II participants' descriptions of their experiences of collaboration between these two agencies, and service providers' reflections on this collaboration through a social constructionist focus on professional cultures. From this perspective, as I described in Chapter III, I understood the professional cultures of the Community Agency and the Children's Hospital to constitute unique meaning making contexts and to have shared discourses from which participants speak and act. I sought to describe the professional cultures of the Community Agency and the Children's Hospital, following scholars in the field of interdisciplinary studies (Davis & Sumara, 1997; Klein, 1996), as recognizable in their interactions with each other. From my encounters with the Children's Hospital and the Community Agency, I initially learned of contrasting styles

of dress, physical environments, educational backgrounds, and foci of interventions. In our interviews, young people and their families described Community Agency workers as contributing to putting safety plans into place, organizing meetings, and securing practical resources. In comparison, research participants described expecting Children's Hospital workers to provide conclusive answers. Service providers reflected that families often come to the Children's Hospital seeking expertise, despite staff efforts to share treatment responsibilities with the Community Agency.

It appeared that, following Kleinman's (1978) definition of professional cultures as being "built out of meanings, behavioural norms and the like" (p. 86), the meanings given to work at the Children's Hospital reflected expertise in assigning conclusive answers and an assumed expertise, which reflected a certain "*brand recognition*." In comparison, work at the Community Agency carried meanings, as described by service users, such as organizing practical aspects of care. These meanings may reflect behavioural norms such as focusing on reducing immediate risk as opposed to client engagement and support. These meanings and behavioural norms may reflect "values, beliefs, customs and behaviours" (Hall, 2005, p. 188) that may significantly differ between the professional cultures of the Community Agency and the Children's Hospital. In reference to young people and their families' understandings of their diagnoses, it appeared that my research respondents expected the Children's Hospital to have the answers to the puzzles of their distressing mental health symptoms. At the same time, respondents often found the practical work of Community Agency staff as being the most helpful in adapting to and confronting these symptoms. These experiences correspond to writing that demonstrates how persons with the status of service user (e.g., patients, clients) or who display behaviours that break with certain behavioural norms (e.g., remaining mute in social situations) may receive different labels based on discourses that shape the settings in which these behaviours are understood and responded to such as community clinics, hospitals, and religious communities (Dickens & Picchioni, 2012; L. Kirmayer & Young, 1999). I define discourse, following Burr (2003), as "a set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of events" (p. 64). As Hare-Mustin (1994) demonstrates, certain discourses make certain ideas more prominent than others. In my research, I explored discourses as evidenced by social practices deployed by members of the Children's Hospital and the Community Agency and as described by young people and their families seeking interagency collaborative treatment from service providers within the two organizations.

In the case of service providers working in the Community Agency, respondents described practices such as organizing meetings and securing practical resources. I also noted the practice of prioritizing the engagement of clients as part of avoiding harm. These practices resemble what Madsen and Gillespie (2014) have storied previously as community-based workers “walking and talking” beside their clients. This practice of walking and talking, as Madsen (2014) points out, constitutes a subordinate class in social service systems, an observation reinforced by both Community Agency and Children's Hospital service providers when they spoke about hierarchies as part of their reflection on their experiences of professional cultures. These workers' responses provided a more complex story of these hierarchies when they talked about the advent of collaborative programs between the two agencies, which also prompted changing interactions between the Community Agency and the Children's Hospital. Workers also spoke about increased sensitivity to collaboration in colleagues who had worked in both settings.

In comparison, clients and service providers described the work done by the Children's Hospital as involving conclusions about the meaning of symptoms, as being the work of experts, and as having a certain “*brand recognition*,” which all appear to contribute to a story of expertise. This story resonates with my experience of the Children's Hospital's environment as a formal clinical environment focused on acute risk reduction and suggesting conclusive solutions. These practices also correspond to practices that Wampold (2013) identifies as “Medicalized” and that Madsen and Gillespie (2014) describe as sitting and talking. In these practices, clients are expected to come to the offices of service providers to be evaluated and instructed on solutions. The differing practices of the Community Agency and the Children's Hospital are especially compelling when presented in interaction. Although the Children's Hospital does offer treatment, it is interesting to note the service provider who describes people as seeking only assessment from the Children's Hospital, which is what is usually offered. It is also interesting in the context of Stage I families' recollections of diagnoses as keys to the system and as providing conclusions about somatic processes.

In my explorations of the experiences of both veteran and new-to-treatment young people and their families with interagency collaboration in River City, I heard that families seek connections and support in managing their children's care. Families seeking connections occurred in the context of diagnoses that young people and their families described on a spectrum from providing answers to troubling symptoms, to providing keys to a system, or to

being merely associated with somatic processes such as taking medication or being unable to pay attention. These experiences occurred in the context of merging professional cultures of the Children's Hospital and the Community Agency that include aspects of providing answers and being sought out as experts, to focusing on engagement and organizing treatment systems. As I described in Chapter I, these experiences occurred within the changing mental health system in River City with the Children's Hospital and the Community Agency seeking closer connections and the development of vertical integration (Boydell et al., 2009) between these and other services.

## CHAPTER VIII: DISCUSSION AND CONCLUSIONS.

In this dissertation, I report my investigation of veteran and new-to-treatment youth and their parents' experiences of interagency collaboration in the context of a psychiatric diagnosis and subsequent treatment by the Children's Hospital and the Community Agency. These agencies are increasingly collaborating in the context of increased integration between community- and hospital-based mental health services. Increased integration follows from trends in legislation in the province of Ontario concerning national attention to child and adolescent mental health (Bartram et al., 2012; Boydell et al., 2009; Children's Mental Health Ontario, n.d.; Kirby & Keon, 2006; Kutcher & McLuckie, 2013). In order to investigate such family experiences, I sought to answer the following research questions:

1. How do families experience collaborative care in their interactions with various professionals (e.g., school<sup>17</sup>, community, medical practitioners) regarding their child's psychiatric diagnosis? Specifically,
  - a. How do young people and their families who are veterans of interagency collaborative mental health treatment describe their experiences?
  - b. How do new-to-treatment families describe continuity between the various professionals who collaborate to provide mental health care for their children?
2. What perspectives on collaborative care do community and medical professionals offer in response to this study's descriptions of new-to-treatment and veteran adolescent and family experiences?

I used a social constructionist conceptual framework to address these questions. Following from this perspective, I understood the knowledge generated to be contingent on the time and place (i.e., context) of its production. I focused on the concept of professional cultures—communities of professionals who share discourses connected to their specific organizations. To apply this framework, I used a hermeneutic phenomenological methodology (van Manen, 1997) to attend to families' experiences as situated within the context of both the experiences and the context in which I asked about them. In the previous three chapters, I reported how young people and their families described their experiences of informational continuity and interagency collaborative care shared between the Community Agency and the

Children's Hospital, and how service providers responded to these descriptions, within the changing mental health treatment environment of River City, in the context of a psychiatric diagnosis.

### **Discussion of Results**

I investigated young people and their parents' descriptions of their experiences of interagency collaborative mental health treatment, shared between the Community Agency and the Children's Hospital, in the context of a psychiatric diagnosis. I conducted my investigation over three Stages:

- Stage I: Interviews or focus groups with older youth (16 years of age and older) and their parents at least six months after the beginning of their collaborative treatment between the Children's Hospital and the Community Agency,
- Stage II: Interviews at the beginning and end of a 3-month period with emerging adolescents (12 – 14 years of age) and their parents as they began receiving collaborative treatment between the Children's Hospital and the Community Agency, and
- Stage III: Separate presentations and discussions of initial results with service providers at the Children's Hospital and the Community Agency to gather their reflections.

Youth and their parents describe psychiatric diagnoses along a spectrum from diagnoses as pertaining to bodily processes (i.e., from taking medication to being unable to sit still), as keys to additional services, and as potential explanations for troubling symptoms. These results show that young people and their parents take up diagnoses in different ways and these perspectives may be empowering or disempowering as mental health treatment progresses. This finding runs somewhat counter to literature regarding client experiences of psychiatric diagnoses, which reports that more medicalized understandings of diagnoses are associated with lower self-regard, and that uncertainty about diagnoses may be indicative of more agentic responses to being diagnosed as mentally ill (e.g., Moses, 2009). The family understandings of diagnoses that I observed are also interesting in light of previous phenomenological perspectives. For example, Hayne (2003) argues that diagnoses may be experienced by clients as an imposition of medical power onto their stories, that can be deepen their knowledge of what they are experiencing, and

---

<sup>17</sup> Research participants reflected upon their experiences with schools, however this was not the main focus of this

he refers to “healing gained from a diagnosis which made illness evident and treatment possible” (p. 726). Others argue that a practitioner assigning a diagnosis may result in recipients feeling more knowledgeable about their struggles (Moses, 2009, 2011). The spectrum of responses evident in my findings may also be indicative of different stages of treatment as youth move further into the treatment process and associate diagnoses less with potential cures and more with particular bodily processes. These results are especially interesting in light of participants’ stories of diagnoses in Chapter VI where they each describe different orientations to these diagnoses, from a sought-after cure, to an explanation of troubling experiences, to a label given by doctors. These descriptions of diagnoses provide context to my explorations of families’ experiences of interagency collaboration and informational continuity. As I described in Chapter II, previous investigations show that families have difficulties accessing services, service providers talk from different silos, and youth with mental health needs are often not connected to appropriate services in a timely nor efficient manner (Farmer, Burns, Phillips, Angold, & Costello, 2003; Offord, 1987; Pavkov et al., 2012; Reid et al., 2011). On the individual level, young people and their families described having to tell their stories multiple times and feeling that services are disconnected and not centered on their needs (Cohen et al., 2012; O’Reilly et al., 2012). Various authors describe the experiences of families within collaborative care as confusing and non-transparent (Boydell et al., 2006; Raingruber, 2003; Widmark et al., 2013).

In building on these previous findings, I learned that young people and their parents described interagency collaboration by talking about how they experienced seeking connections with and between service providers. Similar to the work of Cohen et al., (2012) and Riley et al., (2012) youth and families in this study were called upon to repeat their stories multiple times leading to impressions of disconnected services. Service providers reflecting on these results described the current mental health system in River City as difficult to navigate and haphazard. These service providers described families as in perpetual crisis as a result of difficulties navigating mental health treatment that resulted in young people and their families bouncing around various services. These reflections reinforced the notion that families feel that service providers are collaborating when they witness direct evidence of these collaborations and that in my study such evidence was not commonly experienced. These observations by families give credence to the idea that young people and their families should be considered partners in their

care (e.g., Gehart, Ratliff, & Lyle, 2001; Murphy, Gardner, Kutcher, Davidson, & Manion, 2010). I identified experiences of collaborative partnership, where young people and families felt supported in managing their care, to their knowledge that all of their service providers were sharing information.

Continuity of care is an important construct that helps address families' experiences of mental health services (Haggerty et al., 2013; Tobon et al., 2014). In this investigation, I focused on one dimension of this construct, informational continuity, to allow me to consider how families experienced service providers sharing information while these service providers considered these families' social contexts (Tobon et al., 2013).

In my conversations with young people and their parents regarding their experiences of service providers sharing information to provide treatment relevant to research participants' social contexts, I found that families appreciated when this treatment supported their management of care. This support involved empowering young people and their families to make choices relevant to their treatment. Lack of support often resulted in families accessing many disconnected services. My findings duplicate Reid et al.'s (2011) finding that families accessed many services at once for a similar problem. They also conform to the findings of various other authors (Boydell et al., 2006; Pavkov et al., 2012; Raingruber, 2003), that depict families feeling lost in a system that appeared opaque and confusing to them.

Service providers, when reflecting on my depiction of families' experiences of accessing multiple services, described their experiences of families trying to maximize the services they were receiving and trying to speed up wait-lists by accessing more acute services (e.g., an Emergency Department). Providers acknowledged the unspoken understanding that, in the current system, many families are expected to be their own case managers. Service providers reflected on how difficult this role may be for families who are already coping with supporting their child, who is struggling, and speculated that families may feel abandoned in this process. According to the families and service providers in this study, child and adolescent mental health services in River City are not yet patient-centered. Families and service providers described "*fumbling through*" systems that sometimes felt like "*punishments*" with repeated assessments and dead ends being offered in response to perpetual family crises.

To understand the current state of providers working together, I argue that an important aspect of interagency collaboration is the concept of professional cultures (Hall, 2005), as investigated from a social constructionist perspective (Burr, 2003). I investigated these questions

through a hermeneutic phenomenological approach (Ajjawi & Higgs, 2007; Lavery, 2003; van Manen, 1997), wherein I considered both the context within which I was investigating, as well as the context that participants were speaking from, in order to contextualize or situate (Haraway, 1988) my results. I situated my findings that young people and their families, in the contexts of their varied understandings of, and expectations for, the treatment of a psychiatric diagnosis, seek connections and hope for support in managing their difficulties.

I considered family descriptions of the social practices of their service providers, and service providers' reflections on these social practices, to be located within the respective professional cultures of the Children's Hospital and the Community Agency. Families described Children's Hospital staff as engaging in practices of collecting previous treatment information, assigning diagnoses, and prescribing both medications and other treatments for psychiatric symptoms. Conversely, families described Community Agency staff as organizing care through securing material resources (e.g., clothes and a lockbox), helping youth ask for what they want, and organizing meetings of multiple service providers to organize collaborative care.

Service providers reflected on these family observations by describing hierarchies within mental health services that resulted in Children's Hospital staff communicating selectively with only some service providers; thus, making themselves less accessible. Service provider respondents framed these hierarchies within the current phenomenon of their "*brand recognition*" as the experts, and community expectations for assessment and conclusive answers from them, which contributed to the increased demand for Children's Hospital mental health services within River City. The family experiences and service provider reflections resonated closely with my own experiences of the Children's Hospital and the Community Agency as student, researcher, and employee. Their respective professional cultures appear to be structured along discursive lines where the Children's Hospital is thought to offer solutions, and following various authors' observations in similar contexts, community-based services are undervalued in favor of medicalized services (Gehart, 2012; Madsen, 2014; Paré, 2009; Strong & Gaete, 2012; Wampold, 2013). At the same time, workers from both the Community Agency and the Children's Hospital described increased instances of collaboration between their services and stated their preference for these collaborative approaches. These reflections lend credence to my intention of exploring collaboration, as opposed to seeing community-based services as subversive reactions to medical approaches.

### **Current Developments in River City's Mental Health Services**

Over the three years of my collecting data and writing this dissertation, significant changes continued to occur in the organization of River City's mental health services for children and youth. For example, at the time that this research was concluding, the Children's Hospital, under a new chief of psychiatry and in combination with the Mental Health Hospital, conducted consultations through surveys, focus groups, and individual interviews with service providers (n=580), youth, and families (n=201) (Children's Hospital and the Mental Health Hospital initiative [Healthy Minds<sup>18</sup>, raw data], 2015). Investigators conducted a thematic analysis of these interviews and identified the top themes of these groups. Researchers reported a number of concerns that were similar to my findings. In particular, these investigators reported that 87.8% of service provider respondents identified "Address Service Gaps" as a major theme to address in the strategic plan; whereas, the authors reported that only 50% of parent/youth respondents described service gaps as a major concern. These findings show that while service providers recognize there are gaps in services, service users do not describe their predominant concern as gaps in services. In comparison to the results of my investigation, it is interesting to note that service providers described families accessing multiple services (e.g., going to the Emergency Department while on waiting lists) as problematic; whereas, families described accessing multiple services as simply providing their own continuity.

The issue of families accessing multiple services and having to be their own case managers is reinforced by Healthy Minds researchers reporting that 100% of youth and family respondents and 85.4% of service provider respondents described "Access and Wait Times" as a major concern (Healthy Minds [Raw data], 2015). This corroborated my findings that when asked about collaboration, families prioritized getting appointments with service providers, and were more interested in talking about being connected to services than collaboration per se. My results demonstrate that families were less concerned by how their service providers actually connected to each other and more impressed by evidence of connections actually occurring. Investigators from the Children's Hospital also report that youth and families (85.4%) and service providers (83.3%) were almost equal in their endorsement of the theme of "Improve Communication and Information Sharing." On the other hand, in the Healthy Minds (2015) results, families (66.7%) reportedly endorsed the theme "Improve Balance Between Assessment and Treatment" at a significantly higher rate than service providers (46.3%). These findings

---

<sup>18</sup> Pseudonym for an initiative between the Children's Hospital and the Mental Health Hospital in River City

support my report that families are generally more concerned about feeling that they knew how to move treatment forward whereas service providers are concerned with individual interventions. These results may also speak further to professional cultures focused on providing answers such as diagnostic clarity as opposed to organizing and engaging families.

In response to the findings of their research, staff at River City's Children's Hospital and Mental Health Hospital Youth Service developed a strategic plan to reorganize children and youth mental health services. These reorganizations are taking place in tandem with the reorganization of children and youth mental health agencies under specific *lead agencies* (Children's Mental Health Ontario, 2013). The Community Agency is now the lead agency, responsible for distributing child and youth mental health services in River City. The Children's Hospital has adopted a model to have parents and young people more quickly choose the services they require. This approach, called the Choice and Partnership Approach (CAPA) (Fuggle et al., 2015; Robotham, James, & Cyhlarova, 2010; York & Kingsbury, 2013) involves families who are referred by their family physician being able to access immediate appointments to discuss their concerns and choose services that are most relevant to their current concerns. The Children's Hospital has also committed to further engagement with young people and their families and improvement of care in psychiatric emergencies so that families will not visit the emergency department numerous times to access mental health services, as some of my research families described doing. These changes have contributed further to the vertical integration of services in River City; they build upon previous efforts to establish a system of care that involves the Community Agency. The implementation of the CAPA approach is beginning as I conclude the writing of this dissertation.

### **Language Use**

In my research above, I focused on how both service users and service providers described their experiences of a system where community- and hospital-based service providers are increasingly encouraged to collaborate. In this work, I depicted the descriptions of research participants as reflective of their experiences and attempted to situate my perspective in collecting and analyzing these results. However, with attention to discourse, the words that research participants used to describe their experiences are reflective of the cultural repertoires—including beliefs about health, illness, and what makes a good life (Burr, 2003; Leonard, 1996)—available to them.

I heard from young people and their families that mental health services often appeared inaccessible and access appeared confusing. At the same time, I heard from service providers and witnessed changes in the current mental health system in River City that there is a larger emphasis being put on giving families choices in their mental health services. When one reflects on the different meanings of the terms “service user”, “patient” and “client” as described in Chapter III, it appears that the notion of a passive client is being eclipsed by the notion of a more active and purposeful “service user” as the CAPA approach is implemented to give more control to young people and their families of the services they receive. It is important to note though that the appearance of choice may be experienced differently by service users depending on their means and experience of access to mental health systems. The notion of agency, or the ability to intentionally influence “one’s functioning and life circumstances” (Bandura, 2006, p. 164), is differently available to persons dependent on their socioeconomic conditions to the extent that it influences even physical health status (Kirmayer, 2005; Petanidou, Mihas, Dimitrakaki, Kolaitis, & Tountas, 2014). Differing levels of agency may cause problems given increased emphasis on persons having to ask for what they need. This observation is demonstrated by an exploration of the word *Philanthropy* which shows that more contemporary definitions move from a pursuit of universal good to an obligation to meet a communicated need (Sulek, 2010). Communicating need may be problematic however when one considers how the word *dependency* has increasingly taken on negative connotations such that relying on government agencies and the services they provide has been increasingly constructed as the result of negative character traits (Fraser & Gordon, 1992).

The words service users and service providers used to describe their movement between hospital-and community based mental health services provides some indication of a move towards increased emphasis on accountability for service users. For example, when a research participant experienced the lack of communication between services as a “*punishment*”, when a service provider described the demand for Children's Hospital based services as “*brand recognition*” and when another service provider described how disempowered families can feel when told they are in control of their care, there are indications that services increasingly rely on service users to make the right choices instead of seeing people who access services as vulnerable “patients” or “clients” who deserve quality care. These experiences point to a system which may be moving towards an emphasis on service users’ choices and a de-emphasis on what service users need or are entitled to.

### **Conclusion**

Changes occurring concurrent to my research in River City's child and adolescent mental health services, and the research underlying these changes, also lends significance to my pursuit of further understanding of families' experiences of interagency collaboration. Results from unpublished research conducted by the Healthy Minds initiative (2015) in River City demonstrate that families prioritize improved access, communication between service providers, and a balance between assessment and intervention. In response, collaborative efforts between the Children's Hospital, the Mental Health Hospital, and the Community Agency have prioritized a model of service organization that further operationalizes an increased focus on patient-centered assessment and treatment. Taken together, the results of my research and current events in River City show a need for increased attention to bolstering young people and their families' abilities to manage their mental health treatment, and for Children's Hospital and Community Agency service providers to continue working to share expertise across their respective professional cultures, and to increase their efforts towards collaboration.

### **Implications**

The findings of this study highlight the key processes of interagency collaboration based on the accounts of five young people and seven of their parents. My findings are qualitative in nature; therefore, I make no claims that my findings apply to all instances of interagency collaborative mental health care. However, my findings indicate three key considerations regarding families' experiences of interagency collaboration between community-and hospital-based children's mental health services:

- Young people and their parents seek evidence of connection when their care is shared by multiple practitioners, and when this evidence is lacking, families seek services in a constant crisis mode;
- Families feel that they can manage their child's care best, when service providers visibly share information; and
- The walking and talking and sitting and talking professional cultures of agencies are more helpful when connections are forged between these cultures.

**Implications for counsellor/psychotherapist training.** In the counselling profession, a shift is occurring, because counsellors are now eligible to join the regulated healthcare profession of psychotherapists in Ontario. This shift involves a move from psychotherapy providers operating in separate silos to the development of a regulated college of psychotherapists

(Transitional Council of the College of Registered Psychotherapists and Mental Health Therapists of Ontario & Form, 2011). The move to a college of psychotherapists follows a global move towards more bureaucratic oversight of psychotherapeutic work (Holmesland, Seikkula, Nilsen, Hopfenbeck, & Erik Arnkil, 2010), and a move toward multidisciplinary teams that transcend/permeate the walls of institutions (CCMHI, 2005). The research I describe contributes to the education of practitioners who must become competent in collaborating with other professionals (Transitional Council of the College of Registered Psychotherapists and Mental Health Therapists of Ontario & Form, 2011). In particular, my results provide concrete tools, contextualized in the real worlds of current practitioners and clients, to help the future psychotherapists of Ontario to work collaboratively towards supporting young people and their families seeking treatment for mental health diagnoses. This work is especially relevant because it reinforces the findings of previous scholars who argue that counsellors must become fluent in the languages of different professional cultures to more effectively collaborate (e.g., Arthur & Russell-Mayhew, 2010; Thannhauser, Russell-Mayhew, & Scott, 2010).

**Implication for counsellors engaging in interagency collaboration.** As described above, counsellors and psychotherapists are increasingly being integrated into mainstream mental health services in Ontario. This integration brings with it the challenge of becoming conversant in many different professional cultures (Arthur & Russell-Mayhew, 2010) and in being aware of one's own professional identity (B.Davis & Sumara, 1997; Gazzola & Smith, 2007). As counsellors and psychotherapists become integrated into public mental health systems, it is important to recognize not only what we contribute to the field, but also how our contributions interface with those of other professions. As I demonstrate in this dissertation, young people and their families seek evidence of connections between practitioners, which is made visible by having administrative procedures such as signing consent forms for sharing information, by practical acts such as talking about medication increases and by buying tools to assist in safety planning. As counsellors, educated in a sitting and talking mode of intervention (i.e., having clients visit us in offices), we may not always think of such walking and talking interventions as ensuring that families' basic needs are met. With the integration of the counselling profession into public mental health systems, these considerations become increasingly important. It is, therefore, necessary for counsellors to engage with other professionals, through methods such as co-therapy and cross-discipline supervision, such as social workers, psychologists, and physicians to learn about the unique contributions of these

professionals within interagency collaborative relationships. It is especially of note that young people and their families did not focus primarily on specific counselling techniques in their stories of interprofessional, interagency collaboration. Rather, they spoke about the more practical aspects of moving through systems and feeling that they were able to manage care in a way that worked with the context of their lives. Such findings signal the need for further work to ensure that as counsellors working in interagency teams, we make sure to consider our treatments within the psychosocial circumstances of clients' lives with attention to integrating the contributions of other involved professionals. I argue that this entails attempting to understand and be hospitable to the knowledge of other professions (Larner, 2003) while understanding our own knowledge not as subverting that of others, but as enabling us to work alongside our clients and other professionals in their lives.

**Implication for service users who are receiving collaborative care.** The results of my research speak to the realities of a system that service users often experience as opaque. It is important for service users to be made aware of how journeys through the mental health system work. One important example of this is “journey mapping” (Davey et al., 2013; Tilleczeck & Lezeu, 2014), an approach where young people's journeys through mental health systems are depicted visually in ways that highlight what gets in the way and what helps (i.e., barriers and facilitators for) young people and their families to get into and engage in services. Three important points from my research that would be useful to young people and their families engaged in mental health services would be the following:

- When you are struggling with mental health difficulties, there are many parts to these difficulties, a diagnosis does not describe all of these parts but it does describe what treatments the people giving this diagnosis think you need. It is your right to know what these treatments are and how they work;
- Service providers in different agencies are often very busy. It is important to make sure that they know about what you've already tried. It is your right for your service providers to talk to each other and to choose which service providers talk to each other about what information;
- Service providers in different agencies may have different ways of explaining your concerns and the treatments they are offering. It is important to share your understanding of what they are doing and what you have been told before. It is

your right to know how people understand what you are going through and what they think you need to get help.

### **Limitations**

The nature of a phenomenological hermeneutic inquiry is that it is unavoidably situated within the time and place of the particular study (Fischer, 2009). In my research, these limitations played out in the fact that I interviewed young people and their families in the context of a changing system and regarding the time periods of their treatments, both past and those that clients were just entering. In addition, because I did not conduct participant observations, all findings of this study are based on recollections of participants' previous experiences, co-constructed with the researcher. This co-construction was, naturally, influenced by my dual roles as a researcher and service provider within the children's mental health system of River City. While I have tried to mediate this influence by exposing how the knowledge I produced is situated in my particular roles, families' knowledge of my work at the Children's Hospital may well have influenced what they chose to share or not share. I have attempted to account for these influences by speculating upon the discourses that underlay the results. However, I did not engage in a full discourse analysis of the data and did not capture naturally occurring speech, which is generally the hallmark of such inquiries (e.g., Avdi & Georgaca, 2007). Overall, I present my results to demonstrate a process of thinking about young people and their parents' experiences of interagency collaborative care, rather than a portrayal of the essence of the experience of such care.

**Recommendations for Future Research.** The findings of this research provide a description of young people and their parents' experiences of interagency collaboration through retrospective reflection, descriptions of engaging in these processes, and reflections on these findings by research participants and service providers. The results of this study can be expanded upon by a closer examination of the day-to-day experiences of both service providers and client families through the use of participant observation (Tedlock, 2005; Wolcott, 2008).

Previous authors have used participant observation to describe young people's understandings of transformations when taking psychotropic medication (Carpenter-Song, 2009; Jain & Jadhav, 2009), how families from different ethno-cultural backgrounds understand diagnoses such as pediatric bipolar disorder and ADHD (Carpenter-Song, 2007), and the integration of workers from various agencies into a system of care (C. S. Davis, 2013). When

taken together, these ethnographic works describe processes of experiencing specific phenomenon related to the topic at hand. These studies provide rich descriptions of clinical processes that provide more tools for the practitioner's burgeoning toolbox.

Another potential area of exploration would be participants' experiences of relational and managerial continuity (Haggerty et al., 2013), which are dimensions of the continuity of care construct. In this dissertation, I chose not to address these dimensions directly because I focused on families' experiences of processes between agencies, rather than on their experiences with individual workers. Combined with the results of this study, inquiries into client experiences of relational and managerial continuity could further illuminate specific processes of engagement and of delivering diagnoses in relational ways, which would add to our understanding of families' experiences of progress in their treatment journeys.

Finally, an ethnographic inquiry into client experiences of collaboration between specific providers with different professional backgrounds could further illuminate how discourses regarding expertise play out in clinical encounters.

### **Summary and Conclusions**

In this hermeneutic phenomenological study, I described young people and their families' experiences of interagency collaboration in the context of the professional cultures of the River City Children's Hospital and Community Agency. I contextualized my reporting of these experiences by sharing my own experiences of those cultures and by including service provider reflections as prompted by their viewing slides summarizing my initial findings. This research resulted in my understanding that families experience the Community Agency as focused on reinforcing skills and bolstering family supports and the Children's Hospital as focused on diagnosing problems and suggesting solutions. Families described their experiences of seeking connections between agencies as mediated by their impressions of how holistically collaborative efforts met their needs. Families described these efforts as successful when collaboration was visible to them and to the extent that such collaboration helped family members manage overall care and know how to ask for services when needed.

## REFERENCES

- Adair, C. E., McDougall, G. M., Beckie, A., Joyce, A., Mitton, C., Wild, C. T., ... Costigan, N. (2003). History and measurement of continuity of care in mental health services and evidence of its role in outcomes. *Psychiatric Services (Washington, D.C.)*, 54(10), 1351–1356. <http://doi.org/10.1176/appi.ps.54.10.1351>
- Adair, C. E., McDougall, G. M., Mitton, C. R., Joyce, A. S., Wild, T. C., Gordon, A., ... Beckie, A. (2005). Continuity of care and health outcomes among persons with severe mental illness. *Psychiatric Services (Washington, D.C.)*, 56(9), 1061–9. <http://doi.org/10.1176/appi.ps.56.9.1061>
- Ajjawi, R., & Higgs, J. (2007). Using Hermeneutic Phenomenology to Investigate How Experienced Practitioners Learn to Communicate Clinical Reasoning. *The Qualitative Report*, 12(4), 612–638. Retrieved from <http://www.nova.edu/ssss/QR/QR12-4/ajjawi.pdf>
- American Psychiatric Association. (2013). Neurodevelopmental Disorders. In *Diagnostic and Statistical Manual of Mental Disorders*. American Psychiatric Association. <http://doi.org/10.1176/appi.books.9780890425596.dsm01>
- Anderson, H., & Gehart, D. R. (2007). *Collaborative Therapy: Relationships and Conversations that Make a Difference*. Routledge.
- Anderson, H., & Goolishian, H. a. (1988). Human systems as linguistic systems: preliminary and evolving ideas about the implications for clinical theory. *Family Process*, 27(4), 371–93. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/3234525>
- Arthur, N., & Russell-Mayhew, S. (2010). Preparing Counsellors for Interprofessional Collaboration through Supervision and Lateral Mentoring. *Canadian Journal of Counselling / Revue Canadienne de Counseling*, 44(3), 258–271. Retrieved from <http://cjc-rcc.ucalgary.ca/cjc/index.php/rcc/article/view/937>
- Asarnow, J. R., Jaycox, L. H., Duan, N., LaBorde, A. P., Rea, M. M., Murray, P., ... Wells, K. B. (2005). Effectiveness of a Quality Improvement Intervention for Adolescent Depression in Primary Care Clinics. *JAMA*, 293(3), 311. <http://doi.org/10.1001/jama.293.3.311>
- Avdi, E., & Georgaca, E. (2007). Discourse analysis and psychotherapy : A critical review. *Discourse*, 9(June), 157–176. <http://doi.org/10.1080/13642530701363445>
- Bachrach, L. L. (1981). Continuity of care for chronic mental patients: a conceptual analysis. *The*

- American Journal of Psychiatry*, 138(11), 1449–56. <http://doi.org/10.1176/ajp.138.11.1449>
- Bandura, A. (2006). Toward a psychology of human agency. *Perspectives On Psychological Science (Wiley-Blackwell)*, 1(2), 164–180. <http://doi.org/10.1111/j.1745-6916.2006.00011.x>
- Bartram, M., Chodos, H., Gosling, S., Hardie, S. L., Knoops, F., Lapierre, L., ... The Mental Health Commission of Canada. (2012). *Changing directions, changing lives: The mental health strategy for Canada. Mental Health Commission of Canada*. Calgary, Canada. Retrieved from <http://www.cpa.ca/docs/File/Practice/strategy-text-en.pdf>
- Besley, A. C. (2002). Foucault and the turn to narrative therapy. *British Journal of Guidance & Counselling*, 30(2), 125–143. <http://doi.org/10.1080/03069880220128010>
- Blumer, H. (1954). What is Wrong with Social Theory? *American Sociological Review*, 19(1), 3–10. <http://doi.org/10.2307/2088165>
- Boydell, K. M., Bullock, H., & Goering, P. N. (2009). *Getting our acts together : Interagency collaborations in child and youth mental health*. Ottawa, Ontario. Retrieved from [http://www.excellenceforchildand youth.ca/sites/default/files/position\\_integration.pdf](http://www.excellenceforchildand youth.ca/sites/default/files/position_integration.pdf)
- Boydell, K. M., Pong, R., Volpe, T., Tilleczek, K., Wilson, E., & Lemieux, S. (2006). Family perspectives on pathways to mental health care for children and youth in rural communities. *The Journal of Rural Health*, 22(2), 182–188. <http://doi.org/10.1111/j.1748-0361.2006.00029.x>
- Bradford, G. K. (2010). Fundamental Flaws of the DSM: Re-Envisioning Diagnosis. *Journal of Humanistic Psychology*, 50(3), 335–350. <http://doi.org/10.1177/0022167809352007>
- Brown, P. (1995). Naming and Framing : The Social Construction of Diagnosis and Illness. *Journal of Health and Social Behavior*, 35(1995), 34–52. Retrieved from <http://www.jstor.org/stable/2626956>
- Burr, V. (2003). *Social Constructionism*. New York, NY: Routledge.
- Carpenter-Song, E. (2009). Caught in the psychiatric net: Meanings and experiences of ADHD, pediatric bipolar disorder and mental health treatment among a diverse group of families in the United States. *Culture, Medicine and Psychiatry*, 33(1), 61–85. <http://doi.org/10.1007/s11013-008-9120-4>
- Carpenter-Song, E. A. (2007). *Lived experiences of behavioral and emotional disorders in US children and families*. Case Western University. Retrieved from <http://etd.ohiolink.edu/view.cgi?case1178314163>
- Chamberlin, J. (2005). User/consumer involvement in mental health service delivery. *Epidemiol*

- Psichiatr Soc*, 14(1), 10–14. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=15792289](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=15792289)
- Cheng, T. C., & Lo, C. C. (2012). Racial disparities in access to needed child welfare services and worker-client engagement. *Children and Youth Services Review*, 34(9), 1624–1632. <http://doi.org/10.1016/j.childyouth.2012.04.021>
- Children's Mental Health Ontario. (n.d.). Integration of Ontario's Child and Youth Mental Health System, 1–12. Retrieved from [http://www.kidsmentalhealth.ca/documents/Res\\_Integration\\_of\\_Ontarios\\_Child\\_and\\_Youth\\_Mental\\_Health\\_System.pdf](http://www.kidsmentalhealth.ca/documents/Res_Integration_of_Ontarios_Child_and_Youth_Mental_Health_System.pdf)
- Children's Mental Health Ontario. (2013). *Lead Agency Capacity : Guiding the Implementation of New Pathways to Care*. Retrieved from [http://www.kidsmentalhealth.ca/documents/lead\\_agency\\_capacity-guiding\\_the\\_implementation\\_of\\_new\\_pathways\\_to\\_care.pdf](http://www.kidsmentalhealth.ca/documents/lead_agency_capacity-guiding_the_implementation_of_new_pathways_to_care.pdf)
- Christians, C. G. (2005). Ethics And Politics In Qualitative Research. In N. K. Denzin & Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., Vol. 2, pp. 139–164). Thousand Oaks: Sage. Retrieved from [http://www.sagepub.com/sites/default/files/upm-binaries/5317\\_Denzin\\_and\\_Lincoln\\_Chapter\\_6.pdf](http://www.sagepub.com/sites/default/files/upm-binaries/5317_Denzin_and_Lincoln_Chapter_6.pdf)
- Clarke, A. E. (2005). *Situational Analysis: Grounded Theory After the Postmodern Turn*. Thousand Oaks, CA: Sage.
- Cloutier, P., Kennedy, A., Maysenhoelder, H., Glennie, E. J., Cappelli, M., & Gray, C. (2010). Pediatric Mental Health Concerns in the Emergency Department. *Pediatric Emergency Care*, 26(2), 99–106. <http://doi.org/10.1097/PEC.0b013e3181cdcae1>
- Cohen, E., Calderon, E., Salinas, G., SenGupta, S., & Reiter, M. (2012). Parents' Perspectives on Access to Child and Adolescent Mental Health Services. *Social Work in Mental Health*, 10(4), 294–310 17p. <http://doi.org/10.1080/15332985.2012.672318>
- Combs, G., & Freedman, J. (2012). Narrative, Poststructuralism, and Social Justice: Current Practices in Narrative Therapy. *The Counseling Psychologist*, 40(7), 1033–1060. <http://doi.org/10.1177/0011000012460662>
- Costello, E. J., Egger, H., & Angold, A. (2005). 10-year research update review: the epidemiology of child and adolescent psychiatric disorders: I. Methods and public health burden. *J Am Acad Child Adolesc Psychiatry*, 44(10), 972–986.

<http://doi.org/10.1097/01.chi.0000172552.41596.6f>

Creswell, J. W. (2007). *Qualitative Inquiry & Research Design: Choosing Among Five Approaches*. Sage Publications.

Creswell, J. W. (2009). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. SAGE Publications.

Cummings, J. R., Ponce, N. A., & Mays, V. M. (2010). Comparing Racial/Ethnic Differences in Mental Health Service Use Among High-Need Subpopulations Across Clinical and School-Based Settings. *Journal of Adolescent Health*, 46(6), 603–606.

<http://doi.org/10.1016/j.jadohealth.2009.11.221>

Davey, A., Barnard, I., Campbell, J., Leblanc, M., Gulley, K., Fuller, L., & Waters, M. (2013). Kamloops Patient Journey Mapping Report Child and Youth Mental Health, (November 2012).

Davidson, S., & Manion, I. G. I. (1996). Facing the challenge: Mental health and illness in Canadian youth. *Psychology, Health & Medicine*, 1(1), 41–56.

<http://doi.org/10.1080/13548509608400005>

Davis, B., & Sumara, D. (1997). Cognition, Complexity, and Teacher Education. *Harvard Educational Review*, 67(1), 105–126. <http://doi.org/10.17763/haer.67.1.160w00j113t78042>

Davis, C. S. (2013). *Communicating Hope: An Ethnography of a Children's Mental Health Care Team*. Left Coast Press. Retrieved from <https://books.google.ca/books?id=Pc2K0lRD0TYC>

Denzin, N. K. (2009). The elephant in the living room: or extending the conversation about the politics of evidence. *Qualitative Research*, 9(2), 139–160.

<http://doi.org/10.1177/1468794108098034>

Dickens, G., & Picchioni, M. (2012). A systematic review of the terms used to refer to people who use mental health services: User perspectives. *International Journal of Social Psychiatry*, 58(2), 115–122. <http://doi.org/10.1177/0020764010392066>

Duggleby, W. (2005). What about focus group interaction data? *Qualitative Health Research*, 15(6), 832–40. <http://doi.org/10.1177/1049732304273916>

Farmer, E. M. Z., Burns, B. J., Phillips, S. D., Angold, A., & Costello, E. J. (2003). Pathways into and through mental health services for children and adolescents. *Psychiatric Services (Washington, D.C.)*, 54(1), 60–66. <http://doi.org/10.1176/appi.ps.54.1.60>

Fischer, C. T. (2009). Bracketing in qualitative research: conceptual and practical matters.

*Psychotherapy Research : Journal of the Society for Psychotherapy Research*, 19(June

- 2013), 583–590. <http://doi.org/10.1080/10503300902798375>
- Foucault, M. (1984). *The Foucault reader*. New York (Vol. 1). Pantheon Books.
- Fraser, N., & Gordon, L. (1992). A Genealogy of Dependency: Tarcng a Keyword of the US Welfare State. *Signs*, 19(2), 309–336. <http://doi.org/10.1016/j.ejpoleco.2006.08.005>
- Freake, H., Barley, V., & Kent, G. (2007). Adolescents' views of helping professionals: A review of the literature. *Journal of Adolescence*, 30(4), 639–653. <http://doi.org/10.1016/j.adolescence.2006.06.001>
- Fuggle, P., McHugh, A., Gore, L., Dixon, E., Curran, D., & Cutinha, D. (2015). Can we improve service efficiency in CAMHS using the CAPA approach without reducing treatment effectiveness? *Journal of Child Health Care : For Professionals Working with Children in the Hospital and Community*. <http://doi.org/10.1177/1367493514563856>
- Gagné, M. A. (2005). *What is Collaborative Mental Health Care?: An Introduction to the Collaborative Mental Health Care Framework*. Mississauga, ON: Canadian Collaborative Mental Health Initiative. Retrieved from <http://www.shared-care.ca/files/02-Framework-EN.pdf>
- Gazzola, N., & Smith, J. D. (2007). Who do we think we are? A survey of counsellors in Canada. *International Journal for the Advancement of Counselling*, 29(2), 97–110. <http://doi.org/10.1007/s10447-007-9032-y>
- Gehart, D. R. (2012). The Mental Health Recovery Movement and Family Therapy, Part II: A Collaborative, Appreciative Approach for Supporting Mental Health Recovery. *Journal of Marital and Family Therapy*, 38(3), 443–457. <http://doi.org/10.1111/j.1752-0606.2011.00229.x>
- Gehart, D. R., Ratliff, D. a, & Lyle, R. R. (2001). Qualitative research in family therapy: a substantive and methodological review. *Journal of Marital and Family Therapy*, 27(2), 261–74. <http://doi.org/10.1111/j.1752-0606.2001.tb01162.x>
- Gergen, K. J. (1985). The social constructionist movement in modern psychology. *American Psychologist*, 40(3), 266–275. <http://doi.org/10.1037/0003-066X.40.3.266>
- Gergen, K. J. (2010). The Acculturated Brain. *Theory & Psychology*, 20(6), 795–816. <http://doi.org/10.1177/0959354310370906>
- Gergen, K. J., & McNamee, S. (2000). From disordering discourse to transformative dialogue. *Constructions of Disorder: Meaning-Making Frameworks for Psychotherapy*, 333–349. <http://doi.org/10.1037/10368-014>

- Gingerich, W. J., & Eisengart, S. (2000). Solution-Focused Brief Therapy: A Review of the Outcome Research\*. *Family Process*, 39(4), 477–498. <http://doi.org/10.1111/j.1545-5300.2000.39408.x>
- Giorgi, A., & Giorgi, B. M. (2003). The Descriptive Phenomenological Psychological Method. In P. M. Camic, J. E. Rhodes, & L. Yardley (Eds.), *Qualitative research in psychology: Expanding perspectives in methodology and design* (pp. 243–274). Washington, D.C.: American Psychological Association.
- Glisson, C. (2002). The organizational context of children's mental health services. *Clinical Child and Family Psychology Review*, 5(4), 233–53. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12495268>
- Gobo, G. (2008). 7 Entering the Field. In *Doing Ethnography* (pp. 118–134). 1 Oliver's Yard, 55 City Road, London England EC1Y 1SP United Kingdom: SAGE Publications Ltd. <http://doi.org/10.4135/9780857028976.d13>
- Goldman, S. K. (1988). *Series on community-based services for children and adolescents who are severely emotionally disturbed. Crisis Services*. (Vol. 2). Washington, DC: CASSP Technical Assistance Center, GeorgetownUniversity Child Development Center,.
- Groleau, D., Young, A., & Kirmayer, L. J. (2006). The McGill Illness Narrative Interview (MINI): an interview schedule to elicit meanings and modes of reasoning related to illness experience. *Transcultural Psychiatry*, 43(4), 671–691. <http://doi.org/10.1177/1363461506070796>
- Groleau, D., Zelkowitz, P., & Cabral, I. E. (2009). Enhancing generalizability: moving from an intimate to a political voice. *Qualitative Health Research*, 19(3), 416–426. <http://doi.org/10.1177/1049732308329851>
- Guta, A., Nixon, S. A., & Wilson, M. G. (2013). Resisting the seduction of “ethics creep”: Using Foucault to surface complexity and contradiction in research ethics review. *Social Science and Medicine*, 98, 301–310. <http://doi.org/10.1016/j.socscimed.2012.09.019>
- Haene, L. De. (2010). Beyond Division: Convergences Between Postmodern Qualitative Research and Family Therapy. *Journal of Marital and Family Therapy*, 36(1), 1–12. <http://doi.org/10.1111/j.1752-0606.2009.00174.x>
- Haggerty, J. L., Reid, R. J., Freeman, G. K., Starfield, B. H., Adair, C. E., & McKendry, R. (2003). Continuity of care: a multidisciplinary review. *BMJ : British Medical Journal*, 327(7425), 1219–1221. <http://doi.org/10.1136/bmj.327.7425.1219>

- Haggerty, J. L., Roberge, D., Freeman, G. K., & Beaulieu, C. (2012). Experienced continuity of care when patients see multiple providers: A qualitative metasummary. *Ann Fam Med, Under rev*, 262–271. <http://doi.org/10.1370/afm.1499>
- Haggerty, J. L., Roberge, D., Freeman, G. K., & Beaulieu, C. (2013). Experienced continuity of care when patients see multiple clinicians: A qualitative metasummary. *Annals of Family Medicine*, 11(3), 262–271. <http://doi.org/10.1370/afm.1499>
- Hall, P. (2005). Interprofessional teamwork: professional cultures as barriers. *Journal of Interprofessional Care*, 19(1), 188–196. <http://doi.org/10.1080/13561820500081745>
- Haraway, D. J. (1988). Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist Studies*, 14(3), 575–599. <http://doi.org/10.2307/3178066>
- Hayne, Y. M. (2003). Experiencing psychiatric diagnosis: client perspectives on being named mentally ill. *Journal of Psychiatric and Mental Health Nursing*, 10(6), 722–9.
- Heary, C. M., & Hennessy, E. (2002). The Use of Focus Group Interviews in Pediatric Health Care Research. *Journal of Pediatric Psychology*, 27(1), 47–57. <http://doi.org/10.1093/jpepsy/27.1.47>
- Heidegger, M. (1967). *Being and Time*. Blackwell.
- Heller, K. S., & Solomon, M. Z. (2005). Continuity of care and caring: What matters to parents of children with life-threatening conditions. *Journal of Pediatric Nursing*, 20(5), 335–346. <http://doi.org/10.1016/j.pedn.2005.03.005>
- Holland, K. (2007). The Epistemological Bias of Ethics Review: Constraining Mental Health Research. *Qualitative Inquiry*, 13(6), 895–913. <http://doi.org/10.1177/1077800407304469>
- Holmesland, A.-L., Seikkula, J., Nilsen, O., Hopfenbeck, M., & Erik Arnkil, T. (2010). Open Dialogues in social networks: professional identity and transdisciplinary collaboration. *International Journal of Integrated Care*, 10(September), 1–14. <http://doi.org/e53>
- Hübner, L. (2014). Constructing relations in social work: client, customer and service user? The application and relevance of the term user in social work discourse. *Nordic Social Work Research*, 4(2), 87–98. <http://doi.org/10.1080/2156857X.2013.867894>
- Husserl, E. (1977). Cartesian meditations. *The Hague: Nijhoff*. <http://doi.org/10.1007/978-94-017-4952-7>
- Huxham, C. (2003). Theorizing collaboration practice. *Public Management Review*, 5(3), 401–423. <http://doi.org/10.1080/1471903032000146964>

- Huxham, C., & Vangen, S. (2004). Doing things collaboratively: Realizing the advantage or succumbing to inertia? *Organizational Dynamics*, 33(2), 190–201.  
<http://doi.org/10.1016/j.orgdyn.2004.01.006>
- Iachini L., A., Hock M., R., Thomas, M., & Clone, S. (2015). Exploring the Youth and Parent Perspective on Practitioner Behaviors That Promote Treatment Engagement. *Journal of Family Social Work*, 18(1), 57–73. <http://doi.org/10.1080/10522158.2014.974293>
- Jain, S., & Jadhav, S. (2009). Pills that swallow policy: clinical ethnography of a Community Mental Health Program in northern India. *Transcultural Psychiatry*, 46(1), 60–85.  
<http://doi.org/10.1177/1363461509102287>
- Jones, I. R., Ahmed, N., Catty, J., McLaren, S., Rose, D., Wykes, T., & Burns, T. (2009). Illness careers and continuity of care in mental health services: a qualitative study of service users and carers. *Social Science & Medicine* (1982), 69(4), 632–639.  
<http://doi.org/10.1016/j.socscimed.2009.06.015>
- Joyce, A. S., Wild, T. C., Adair, C. E., McDougall, G. M., Gordon, A., Costigan, N., ... Barnes, F. (2004). Continuity of care in mental health services: Toward clarifying the construct. *Canadian Journal of Psychiatry*, 49(8), 539–550. Retrieved from  
<http://www.ncbi.nlm.nih.gov/pubmed/15453103>
- Kates, N., Mazowita, G., Lemire, F., Jayabarathan, A., Bland, R., Selby, P., ... Audet, D. (2011). The evolution of collaborative mental health care in Canada: a shared vision for the future. *Family Medicine*, 56(5), 1–10.
- Kessler, R. C., & Cleary, P. D. (1980). Social Class and Psychological Distress. *American Sociological Review*, 45(3), 463–478. Retrieved from <http://www.jstor.org/stable/2095178> .
- Kipick Cawn, M. (2014). *A phenomenological inquiry to understand environmental workplace factors, academic training readiness, and supervisory needs of interprofessional collaborative counselors*. ProQuest Dissertations and Theses. Retrieved from  
<http://search.proquest.com/docview/1614209171?accountid=13042%5Cnhttp://oxfordsfx.ho>  
[sted.exlibrisgroup.com/oxford?url\\_ver=Z39.88-](http://oxfordsfx.ho)  
[2004&rft\\_val\\_fmt=info:ofi/fmt:kev:mtx:dissertation&genre=dissertations+%26+theses&sid](http://oxfordsfx.ho)  
[=ProQ:ProQuest+Dissertations+%26+Theses+G](http://oxfordsfx.ho)
- Kirby, M. J. L., & Keon, W. J. (2006). *Out of the shadows at last: Transforming mental health, mental illness and addiction services in Canada*. Science And Technology. Senate of Canada.

- Kirmayer, L. J. (2005). Culture, context and experience in psychiatric diagnosis. *Psychopathology*, 38(4), 192–196. <http://doi.org/10.1159/000086090>
- Kirmayer, L., & Young, A. (1999). Culture and context in the evolutionary concept of mental disorder.
- Kitzinger, J. (1995). Qualitative Research: Introducing focus groups. *Bmj*, 311(7000), 299–302. <http://doi.org/10.1136/bmj.311.7000.299>
- Klein, J. T. (1996). *Crossing Boundaries: Knowledge, Disciplinarity, and Interdisciplinarity*. University Press of Virginia.
- Kleinman, A. (1978). Concepts and a model for the comparison of medical systems as cultural systems. *Social Science and Medicine. Part B Medical Anthropology*, 12(C), 85–93. [http://doi.org/10.1016/0160-7987\(78\)90014-5](http://doi.org/10.1016/0160-7987(78)90014-5)
- Kolko, D. J., Campo, J. V., Kilbourne, A. M., & Kelleher, K. (2012). Doctor-Office Collaborative Care for Pediatric Behavioral Problems. *Archives of Pediatric and Adolescent Medicine*, 166(3), 224–231. <http://doi.org/10.1001/archpediatrics.2011.201>
- Korczak, D. J. (2015). Suicidal ideation and behaviour. *Canadian Pediatric Society*, 20(5), 257–264. Retrieved from <http://dx.doi.org/>
- Koren, P. E., Paulson, R. I., Kinney, R. F., Yatchmenoff, D. K., Gordon, L. J., & DeChillo, N. (1997). Service Coordination in Children's Mental Health. An Empirical Study From the Caregiver's Perspective. *Journal of Emotional and Behavioral Disorders*, 5(3), 162–172. <http://doi.org/http://dx.doi.org/10.1177/106342669700500304>
- Kutcher, S., & McLuckie, A. (2013). Evergreen: Creating a Child and Youth Mental Health Framework for Canada. *Psychiatric Services*, 64(5), 479–482. <http://doi.org/10.1176/appi.ps.201100269>
- Kutcher, S., McLuckie, A., Committee, for the C. and Y. A., & Mental Health Commission of Canada. (2010). *Evergreen : A Child and Youth Mental Health Framework for Canada*. Calgary, AB. Retrieved from [http://www.mentalhealthcommission.ca/sites/default/files/Diversity\\_Evergreen\\_Framework\\_Summary\\_ENG\\_0\\_1.pdf](http://www.mentalhealthcommission.ca/sites/default/files/Diversity_Evergreen_Framework_Summary_ENG_0_1.pdf)
- Larner, G. (1996). Narrative child family therapy. *Family Process*, 35(4), 423–440. <http://doi.org/10.1111/j.1545-5300.1996.00423.x>
- Larner, G. (2003). Integrating Family Therapy in Child and Adolescent Mental Health Practice: An Ethic of Hospitality. *Australian & New Zealand Journal of Family Therapy*, 24(4), 211–

217. Retrieved from  
<http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=17649373&site=ehost-live>
- Laverty, S. M. (2003). Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations. *International Journal of Qualitative Methods*, 2(3), 21–35. <http://doi.org/10.1177/160940690300200303>
- Lee, C. M., Schneider, B. H., Bellefontaine, S., Davidson, S., & Robertson, C. (2012). Interprofessional collaboration: A survey of Canadian psychologists and psychiatrists. *Canadian Psychology/Psychologie Canadienne*, 53(3), 159–164.  
<http://doi.org/10.1037/a0027619>
- Leonard, P. (1996). Three discourses on practice: A postmodern re-appraisal. *Journal of Sociology and Social Welfare*, 23(7), 7–26. Retrieved from  
<http://heinonline.org/HOL/Page?handle=hein.journals/jrlsasw23&collection=journals&id=219>
- Lock, A., & Strong, T. (2010). *Social Constructionism: Sources and Stirrings in Theory and Practice*. Cambridge University Press.
- Madsen, W. C. (2009). Collaborative Helping: A Practice Framework for Family-Centered Services. *Family Process*, 48(1), 1–14. <http://doi.org/10.1111/j.1545-5300.2009.01270.x>
- Madsen, W. C. (2014). Taking it to the streets: Family therapy and family-centered services. *Family Process*, 53(3), 380–400. <http://doi.org/10.1111/famp.12089>
- Madsen, W. C., & Gillespie, K. (2014). *Collaborative helping: A strengths framework for home-based services*. Hoboken, New Jersey: John Wiley & Sons, Ltd.
- McLaughlin, H. (2009). What's in a name: "client", "patient", "customer", "consumer", "expert by experience", "service user" - What's next? *British Journal of Social Work*, 39(6), 1101–1117. <http://doi.org/10.1093/bjsw/bcm155>
- McNamee, S., & Gergen, K. J. (1992). *Therapy as Social Construction*. SAGE Publications.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative Data Analysis: An Expanded Sourcebook*. SAGE Publications.
- Miller, A. R., Condin, C. J., McKellin, W. H., Shaw, N., Klassen, A. F., & Sheps, S. (2009). Continuity of care for children with complex chronic health conditions: parents' perspectives. *BMC Health Services Research*, 9(1), 242. <http://doi.org/10.1186/1472-6963-9-242>

- Ministry of Children and Youth Services. (2006). *A Shared Responsibility: Ontario's Policy Framework for Child and Youth Mental Health Ministry*. Toronto, Ontario. Retrieved from <http://www.children.gov.on.ca/htdocs/English/documents/specialneeds/mentalhealth/framework.pdf>
- Monk, G., Winslade, J., & Sinclair, S. (2008). *New Horizons in Multicultural Counseling*. SAGE Publications. Retrieved from <https://books.google.ca/books?id=eSIItKHySCKMC>
- Morgan, D. (1997). *Focus Groups as Qualitative Research*. *Qualitative Research Methods Series, Vol. 16* (Vol. 16). 2455 Teller Road, Thousand Oaks California 91320 United States of America: SAGE Publications, Inc. <http://doi.org/10.4135/9781412984287>
- Morrissey, J. P., Johnsen, M. C., & Calloway, M. O. (1997). Evaluating Performance and Change in Mental Health Systems Serving Children and Youth: An Interorganizational Network Approach. *The Journal of Mental Health Administration*, 24(1), 4–22.
- Morrow, S. L. (2005). Quality and Trustworthiness in Qualitative Research in Counseling Psychology. *Journal of Counseling Psychology*, 52(2), 250–260. <http://doi.org/10.1037/0022-0167.52.2.250>
- Moses, T. (2009). Self-labeling and its effects among adolescents diagnosed with mental disorders. *Social Science and Medicine*, 68(3), 570–578. <http://doi.org/10.1016/j.socscimed.2008.11.003>
- Moses, T. (2011). Parents' conceptualization of adolescents' mental health problems: Who adopts a psychiatric perspective and does it make a difference? *Community Mental Health Journal*, 47(1), 67–81. <http://doi.org/10.1007/s10597-009-9256-x>
- Moustakas, C. (1994). *Phenomenological Research Methods*. SAGE Publications. Retrieved from <https://books.google.ca/books?id=pp11AwAAQBAJ>
- Mulvale, G., Abelson, J., & Goering, P. (2007). Mental health service delivery in Ontario, Canada: how do policy legacies shape prospects for reform? *Health Economics, Policy, and Law*, 2(Pt 4), 363–89. <http://doi.org/10.1017/S1744133107004318>
- Munford, R., & Sanders, J. (2015). Young people's search for agency: Making sense of their experiences and taking control. *Qualitative Social Work*, 14(5), 616–633. <http://doi.org/10.1177/1473325014565149>
- Murphy, A., Gardner, D., Kutcher, S., Davidson, S., & Manion, I. (2010). Collaborating with youth to inform and develop tools for psychotropic decision making. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 19(4), 256–263. Retrieved from

- [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2962538/pdf/cacap19\\_4p256.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2962538/pdf/cacap19_4p256.pdf)
- Naert, J., Roose, R., Rapp, R. C., & Vanderplasschen, W. (2017). Continuity of care in youth services: A systematic review. *Children and Youth Services Review*, 75(2016), 116–126. <http://doi.org/10.1016/j.childyouth.2017.02.027>
- NHS Institute for Innovation and Improvement. (2008). Process Mapping - An Overview. Retrieved November 1, 2016, from [http://webarchive.nationalarchives.gov.uk/20091105204501/http://www.institute.nhs.uk/quality\\_and\\_service\\_improvement\\_tools/quality\\_and\\_service\\_improvement\\_tools/process\\_mapping\\_-\\_a\\_conventional\\_model.html](http://webarchive.nationalarchives.gov.uk/20091105204501/http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/process_mapping_-_a_conventional_model.html)
- O'Donnell, A., Lutfey, K., Marceau, L., & McKinlay, J. (2007). Using Focus Groups to Improve the Validity of Cross-National Survey Research: A Study of Physician Decision Making. *Qualitative Health Research*, 17(7), 971–981. <http://doi.org/10.1177/1049732307305257>
- O'Reilly, M., Vostanis, P., Taylor, H., Day, C., Street, C., & Wolpert, M. (2013). Service user perspectives of multiagency working: A qualitative study with children with educational and mental health difficulties and their parents. *Child and Adolescent Mental Health*, 18(4), 202–209. <http://doi.org/10.1111/j.1475-3588.2012.00674.x>
- Offord, D. R. (1987). Ontario Child Health Study. *Archives of General Psychiatry*, 44(9), 832. <http://doi.org/10.1001/archpsyc.1987.01800210084013>
- Osher, D. M. (2002). Creating comprehensive and collaborative systems. *Journal of Child and Family Studies*, 11(1), 91–99. <http://doi.org/10.1023/A:1014771612802>
- Packer, M. J. (1989). Tracing the hermeneutic circle: Articulating an ontical study of moral conflicts. In R. B. Addison & M. J. Packer (Eds.), *Entering the circle: Hermeneutic investigation in psychology* (pp. 95–118). Albany, NY: State University of New York.
- Paré, D. A. (1995). Of families and other cultures: The shifting paradigm of family therapy. *Family Process*, 34(1), 1–19. Retrieved from <http://onlinelibrary.wiley.com/doi/10.1111/j.1545-5300.1995.00001.x/full>
- Paré, D. A. (2009). Notes from the Basement: Developing Therapist Communities Through Collaborative Practice Groups. *Journal of Systemic Therapies*, 28(3), 89–102. <http://doi.org/10.1521/jsyt.2009.28.3.89>
- Paré, D. A., & Lerner, G. (Eds.). (2004). *Collaborative Practice in Psychology and Therapy*. Binghamton, NY: Haworth Clinical Practice Press.
- Pare, D., Rombach, M., & Sori, C. (2003). Therapeutic letters to young persons. *The Therapist's*

- Notebook for Children and ...*, 1–8. Retrieved from <http://scholar.google.com/scholar?hl=en&btnG=Search&q=intitle:Therapeutic+letters+to+youn+g+persons.#0>
- Pavkov, T. W., Soloski, K. L., & Deliberty, R. (2012). The Social Construction of Reality in the Realm of Children's Mental Health Services. *Journal of Social Service Research*, 38(5), 672–687. <http://doi.org/10.1080/01488376.2012.717864>
- Peek, C. J., & The National Integration Advisory Council. (2011). *Lexicon for Behavioral Health and Primary Care Integration*. Rockville, MD. Retrieved from <https://integrationacademy.ahrq.gov/sites/default/files/Lexicon.pdf>
- Petanidou, D., Mihas, C., Dimitrakaki, C., Kolaitis, G., & Tountas, Y. (2014). Selected family characteristics are associated with adolescents' subjective health complaints. *Acta Paediatrica (Oslo, Norway : 1992)*, 103(2), 201–6. <http://doi.org/10.1111/apa.12466>
- Peterson-Sweeney, K. (2005). The use of focus groups in pediatric and adolescent research. *Journal of Pediatric Health Care*, 19(2), 104–110. <http://doi.org/10.1016/j.pedhc.2004.08.006>
- Petrie, H. G. (1976). Do You See What I See? The Epistemology of Interdisciplinary Inquiry. *Educational Researcher*, 5(2), 9–15. <http://doi.org/10.3102/0013189X005002009>
- Petriglieri, G., & Petriglieri, J. L. (2010). Identity Workspaces : The Case of Business Schools. *Academy of Management Learning & Education*, 9(1), 44–60. <http://doi.org/10.5465/AMLE.2010.48661190>
- Pfeiffer, S. I., & Cundari, L. (2000). Interagency Collaboration. *Special Services in the Schools*, 15(1–2), 109–123. [http://doi.org/10.1300/J008v15n01\\_06](http://doi.org/10.1300/J008v15n01_06)
- Pliszka, S. (2007). Practice Parameter for the Assessment and Treatment of Children and Adolescents With Attention-Deficit/Hyperactivity Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 46(7), 894–921. <http://doi.org/10.1097/chi.0b013e318054e724>
- Poland, B., Graham, H., Walsh, E., Williams, P., Fell, L., Lum, J. M., ... Yardy, G. (2005). “Working at the margins” or “leading from behind”? A Canadian study of hospital-community collaboration. *Health and Social Care in the Community*, 13(2), 125–135. <http://doi.org/10.1111/j.1365-2524.2005.00542.x>
- Potter, J. (2007). *Discourse and Psychology*. SAGE Publications. Retrieved from <https://books.google.ca/books?id=tOeLoAEACAAJ>

- Raingruber, B. (2003). Gaps in Service in the Recognition and Treatment of Depression and Suicidal Ideation Within a Four-County Area. *Perspectives In Psychiatric Care*, 39(4), 151–162. <http://doi.org/10.1111/j.1744-6163.2003.00151.x>
- Reaume, G. (2002). Lunatic to patient to person: Nomenclature in psychiatric history and the influence of patients' activism in North America. *International Journal of Law and Psychiatry*, 25(4), 405–426. [http://doi.org/10.1016/S0160-2527\(02\)00130-9](http://doi.org/10.1016/S0160-2527(02)00130-9)
- Reid, G. J., Stewart, S. L., Barwick, M., Cunningham, C. E., Carter, J. R., Evans, B., ... & Zaric, G. S. (2009). Exploring patterns of service utilization within children's mental health agencies. ... *Mental Health* ..., 2(February). Retrieved from [http://medcontent.metapress.com/index/A65RM03P4874243N.pdf%5Cnhttp://www.excellencepourenfantsados.ca/sites/default/files/gai\\_attach/rg-665\\_final\\_outcomes\\_report.pdf](http://medcontent.metapress.com/index/A65RM03P4874243N.pdf%5Cnhttp://www.excellencepourenfantsados.ca/sites/default/files/gai_attach/rg-665_final_outcomes_report.pdf)
- Reid, G. J., Cunningham, C. E., Tobon, J. I., Evans, B., Stewart, M., Brown, J. B., ... Shanley, D. C. (2011). Help-seeking for children with mental health problems: Parents' efforts and experiences. *Administration and Policy in Mental Health and Mental Health Services Research*, 38(5), 384–397. <http://doi.org/10.1007/s10488-010-0325-9>
- Reid, R. J., Haggerty, J. L., & McKendry, R. (2002). *Defusing the confusion: Concepts and measures of continuity of healthcare*. Health Services Research Foundation. Retrieved from [http://www.cfhi-fcass.ca/Migrated/PDF/ResearchReports/CommissionedResearch/cr\\_contcare\\_e.pdf](http://www.cfhi-fcass.ca/Migrated/PDF/ResearchReports/CommissionedResearch/cr_contcare_e.pdf)
- Richardson, L. P., Ludman, E., McCauley, E., Lindenbaum, J., Larison, C., Zhou, C., ... Katon, W. (2014). Collaborative care for adolescents with depression in primary care: a randomized clinical trial. *Jama*, 312(8), 809–816. <http://doi.org/10.1001/jama.2014.9259>
- Richardson, L. P., McCauley, E., & Katon, W. (2009). Collaborative care for adolescent depression: a pilot study. *General Hospital Psychiatry*, 31(1), 36–45. <http://doi.org/10.1016/j.genhosppsych.2008.09.019>
- Robotham, D., James, K., & Cyhlarova, E. (2010). Managing demand and capacity within child and adolescent mental health services: An evaluation of the choice and partnership approach. *Mental Health Review Journal*, 15(3), 22–30. <http://doi.org/10.5042/mhrj.2010.0656>
- Romanow, R. J., & Health Canada. (2002). *Building on Values: The future of Health Care in Canada*. Retrieved from <http://publications.gc.ca/site/eng/237274/publication.html>
- Saldana, J. (2012). *The Coding Manual for Qualitative Researchers*. SAGE Publications.

Retrieved from <https://books.google.ca/books?id=V3tTG4jvgFkC>

- San Martín-Rodríguez, L., Beaulieu, M.-D., D'Amour, D., & Ferrada-Videla, M. (2005). The determinants of successful collaboration: A review of theoretical and empirical studies. *Journal of Interprofessional Care, 19 Suppl 1*(May), 132–47. <http://doi.org/10.1080/13561820500082677>
- Schroeder, R. E., Morrison, E. E., Cavanaugh, C., West, M. P., & Montgomery, J. (1999). Improving communication among health professionals through education: a pilot study. *The Journal of Health Administration Education, 17*(3), 175–198.
- Schwandt, T. A. (2000). Three epistemological stances for qualitative inquiry. In *Handbook of qualitative research* (Vol. 2, pp. 189–213). Sage Publications, Inc.
- Schwartz-Shea, P., & Yanow, D. (2012). *Interpretive Research Design: Concepts and Processes*. Routledge.
- Seidman, I. (2006). *Interviewing as Qualitative Research: A Guide for Researchers in Education and the Social Sciences*. Teachers College Press.
- Shaffer, D., Pfeffer, C. R., & Work Group on Quality Issues. (2001). Practice Parameter for the Assessment and Treatment of Children and Adolescents With Suicidal Behavior. *J. AM. ACAD. CHILD ADOLESC. PSYCHIATRY, 40*(7 Supplement), 24S–51S. Retrieved from [https://www.aacap.org/App\\_Themes/AACAP/docs/practice\\_parameters/suicidal\\_behavior\\_practice\\_parameter.pdf](https://www.aacap.org/App_Themes/AACAP/docs/practice_parameters/suicidal_behavior_practice_parameter.pdf)
- Shaw, I. (2008). Ethics and the Practice of Qualitative Research. *Qualitative Social Work, 7*(4), 400–414. <http://doi.org/10.1177/1473325008097137>
- Shevell, M. I. (2009). What do we call “them”? The “patient” versus “client” dichotomy. *Developmental Medicine and Child Neurology, 51*(10), 770–772. <http://doi.org/10.1111/j.1469-8749.2009.03304.x>
- Simmons, P., Hawley, C. J., Gale, T. M., & Sivakumaran, T. (2010). Service user, patient, client, user or survivor: describing recipients of mental health services. *The Psychiatrist, 34*(1), 20–23. <http://doi.org/10.1192/pb.bp.109.025247>
- Smith, D. E. (1978). ‘K is Mentally Ill’ the Anatomy of a Factual Account. *Sociology, 12*(1), 23–53. <http://doi.org/10.1177/003803857801200103>
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. SAGE Publications.
- Spector, N. M. P. (2008). De-centering and de-triangulating: The role of helpful uncertainty in

- working with attention deficit/hyperactivity disorder. *Journal of Systemic Therapies*, .27(3), pp. <http://doi.org/10.1521/jsyt.2008.27.3.64>
- Spenser, H. R., Lipton, H., Steele, M., Stretch, N., McGrath, P., & Gilles, A. (2006). *Canadian Collaborative Mental Health Initiative. Establishing collaborative initiatives between mental health and primary care services for children and adolescents. A companion to the CCMHI planning and implementation toolkit for health care providers an*. Mississauga, ON. Retrieved from [http://www.shared-care.ca/files/EN\\_CompanionToolkitforChildrenandAdolescents.pdf](http://www.shared-care.ca/files/EN_CompanionToolkitforChildrenandAdolescents.pdf)
- Stanley, D. (2006). Comparative dynamics: Healthy collectivities and the pattern which connects. *Complicity: An International Journal of Complexity and Education*, 3(1), 73–82.
- Strong, T., Gaete, J., Sametband, I. N., French, J., & Eeson, J. (2012). Counsellors Respond to the DSM-IV-TR. *Canadian Journal of ...*, 46(2), 85–106. Retrieved from <http://cjc-rcc.ucalgary.ca/cjc/index.php/rcc/article/view/1556>
- Strong, T., & Gale, J. (2013). Postmodern clinical research: In and out of the margins. *Journal of Systemic Therapies*, .32(2), pp. <http://doi.org/10.1521/jsyt.2013.32.2.46>
- Stroul, B. A., & Blau, G. M. (Eds.). (2008). *The system of care handbook: Transforming mental health services for children, youth, and families*. McLean, VA, United States: Paul H Brookes Publishing.
- Sulek, M. (2010). On the Modern Meaning of Philanthropy. *Nonprofit and Voluntary Sector Quarterly*, (2006), 193–212. <http://doi.org/10.1177/0899764009333052>
- Tannen, D. (1989). *Talking Voices: Repetition, Dialogue and Imagery in Conversational Discourse*. Cambridge University Press. Retrieved from <https://books.google.ca/books?id=MuaMgeJ4FF8C>
- Tedlock, B. (2005). The observation of participation and the emergence of public ethnography. *The Sage handbook of qualitative research*, pp. 467–481. *The SAGE Handbook of Qualitative Research*, 151–172.
- Thannhauser, J., Russell-Mayhew, S., & Scott, C. (2010). Measures of interprofessional education and collaboration. *Journal of Interprofessional Care*, 24(4), 336–349. <http://doi.org/10.3109/13561820903442903>
- Tilliczek, K., & Lezeu, K. (2014). Journeys in Youth Mental Health. Retrieved April 4, 2015, from <http://www.cea-ace.ca/education-canada/article/journeys-youth-mental-health>
- Tobon, J. I., Reid, G. J., & Brown, J. B. (2015). Continuity of Care in Children's Mental Health:

- Parent, Youth and Provider Perspectives. *Community Mental Health Journal*, 51(8), 921–930. <http://doi.org/10.1007/s10597-015-9873-5>
- Tobon, J. I., Reid, G. J., & Goffin, R. D. (2013). Continuity of Care in Children's Mental Health: Development of a Measure. *Administration and Policy in Mental Health*, 41(5), 668–686. <http://doi.org/10.1007/s10488-013-0518-0>
- Tobon, J. I., Reid, G. J., & Goffin, R. D. (2014). Continuity of Care in Children's Mental Health: Development of a Measure. *Administration and Policy in Mental Health and Mental Health Services Research*, 41(5), 668–686. <http://doi.org/10.1007/s10488-013-0518-0>
- Tomanović, S. (2012). Agency in the social biographies of young people in Belgrade. *Journal of Youth Studies*, 15(5), 605–620. <http://doi.org/10.1080/13676261.2012.663893>
- Transitional Council of the College of Registered Psychotherapists and Mental Health Therapists of Ontario, & Form, S. F. (2011). Draft Quality Assurance Regulation. *Quality Assurance*, (416).
- van Manen, M. (1997). *Researching Lived Experience, Second Edition: Human Science for an Action Sensitive Pedagogy*. Left Coast Press.
- Wade, A. (1997). Small acts of living: Everyday resistance to violence and other forms of oppression. *Contemporary Family Therapy*, 19(1), 23–39. <http://doi.org/10.1023/A:1026154215299>
- Waibel, S., Henao, D., Aller, M.-B. B., Vargas, I., Vázquez, M.-L., & Vázquez, M. L. (2012). What do we know about patients' perceptions of continuity of care? A meta-synthesis of qualitative studies. *International Journal for Quality in Health Care*, 24(1), 39–48. <http://doi.org/10.1093/intqhc/mzr068>
- Wampold, B. E. (2013). *The Great Psychotherapy Debate: Models, Methods, and Findings*. Mahwah, NJ: Laurence Erlbaum Associates, Inc., Publishers.
- Ware, N. C., Tugenberg, T., Dickey, B., & McHorney, C. a. (1999). An ethnographic study of the meaning of continuity of care in mental health services. *Psychiatric Services (Washington, D.C.)*, 50(3), 395–400. <http://doi.org/10.1176/ps.50.3.395>
- Wear, D. (2004). Toward negative capability: Literature in the medical curriculum. *Curriculum Inquiry*, 34(2), 169–184. <http://doi.org/10.1111/j.1467-873X.2004.00285.x>
- White, D. (1992). (DE)-Constructing Continuity of Care: The Deinstitutionalization of Support Services for People with Mental Health Problems. *Canadian Journal of Community Mental Health*, 11(1), 85–99. <http://doi.org/10.7870/cjcmh-1992-0006>

- White, M. (2007). *Maps of Narrative Practice*. W.W. Norton & Company.
- White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. Norton.
- Whittemore, R., Chase, S. K., & Mandle, C. L. (2001). Validity in qualitative research. *Qualitative Health Research*, 11(4), 522–537. <http://doi.org/10.1177/104973201129119299>
- Widmark, C., Sandahl, C., Piuva, K., & Bergman, D. (2013). Parents' experiences of collaboration between welfare professionals regarding children with anxiety or depression - an explorative study. *International Journal of Integrated Care*, 13(4), 1–12. <http://doi.org/10.5334/ijic.986>
- Winters, N. C., & Pumariga, A. (2007). Practice parameter on child and adolescent mental health care in community systems of care. *Journal of the American Academy of Child and Adolescent Psychiatry*, 46(2), 284–99. <http://doi.org/10.1097/01.chi.0000246061.70330.b8>
- Wolcott, H. F. (2008). *Ethnography: A Way of Seeing*. Altamira Press.
- Wolf, D. A. P. S., Dulmus, C. N., Maguin, E., & Cristalli, M. (2014). Do Organizational Culture and Climate Matter for Successful Client Outcomes? *Research on Social Work Practice*, 24(6), 670–675. <http://doi.org/10.1177/1049731513506616>
- York, A., & Kingsbury, S. (2013). *The Choice and Partnership Approach: A service transformation model*. Exeter, UK: CAPA Systems Ltd.

**APPENDIX A: MODIFICATIONS TO ORIGINAL RESEARCH DESIGN**

| Stage # | Intended Participants                                            | Intended Source (s)                                          | Intended Data gathering techniques                                                                                                                                                                                                                                                                                                                                                                                               | Modifications                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|---------|------------------------------------------------------------------|--------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1       | Six Adolescent veterans of ADHD treatment and their families.    | Community team                                               | Focus groups                                                                                                                                                                                                                                                                                                                                                                                                                     | <ul style="list-style-type: none"> <li>• Changed participants to adolescent veterans of MH treatment and their families. Expanded recruitment to include Community and Hospital teams.</li> </ul>                                                                                                                                                                                                                                                                        |
| 2       | Four families who are new to Children's Hospital ADHD treatment. | Community based team and Children's Hospital based ADHD team | <p>Participant observation by researcher participation in introductory sessions.</p> <p>Three semi-structured interviews:</p> <p>A. Problem history interview (before the introductory session);</p> <p>B. Interpersonal process recall session (following the first substantial clinical meeting);</p> <p>C. Reflection on the meaning of their experience (6 months after their initial contact with Hospital based team).</p> | <ul style="list-style-type: none"> <li>• Added Children's Hospital mood and anxiety clinic as a recruitment source.</li> <li>• Eliminated Interpersonal Process Recall session (interview 2) and initial participation in interview sessions.</li> <li>• Reduced time between initial interview and final interview from six to three months.</li> <li>• Reduced recruitment to three families.</li> <li>• Added compensation to families for each interview.</li> </ul> |
| 3       | Stage Two Families, community, and medical practitioners.        |                                                              | Separate homogeneous focus groups based on participant background.                                                                                                                                                                                                                                                                                                                                                               | <ul style="list-style-type: none"> <li>• Changed focus groups to brief consultations/ telephone follow-ups.</li> </ul>                                                                                                                                                                                                                                                                                                                                                   |

**APPENDIX B: INTERVIEW GUIDES****INTERVIEW GUIDES FOR STAGE I****Focus group question guide (Adolescents & Parents)*****Adolescents***

1. How would you describe what brought you to seek help from the service providers involved in your treatment?
2. How did you first learn about the diagnosis you have been given?
3. Does this diagnosis describe what you are/were concerned about?
4. What, if anything, changed after you learned about your diagnosis?
5. Who helped you with the problems associated with your diagnosis?
6. Did you feel like the people who helped you with your diagnosis were talking to each other?
7. Did you ever get confused by the help these people offered? Why? What specifically do you remember them saying?
8. [explanation] Professionals in different mental health services (e.g. hospitals and community centres) are being encouraged to work together to make sure that there are no gaps when people move between services. This is called “continuity of care”.
  - 8a. When you think of gaps between services what comes to mind?
  - 8b. What would you say your service providers did or did not do to make sure there were no gaps between the services you received?

***Parents***

1. How would you describe what brought you to seek help from the service providers involved in your treatment?
2. How did you first learn about the diagnosis which your child has been given?
3. Does this diagnosis describe what you are/were concerned about?
4. What, if anything, changed after you learned about your child’s diagnosis?
5. Who helped your family with the problems associated with your child’s diagnosis?
6. Did you feel like the people who helped you with your child’s diagnosis were talking to each other?

7. Did you ever get confused by the help these people offered? Why? What specifically do you remember them saying?
8. [explanation] Professionals in different mental health services (e.g. hospitals and community centres) are being encouraged to work together to make sure that there are no gaps when people move between services. This is called “continuity of care”.

8a. When you think of gaps between services what comes to mind?

8b. What would you say your service providers did or did not do to make sure there were no gaps between the services you received?

### **Demographic Questionnaires (Adolescents & Parents)**

#### **DEMOGRAPHIC QUESTIONNAIRE (Adolescents)**

Your name:

1) Your current age: \_\_\_\_\_

2) Time since your diagnosis: \_\_\_\_\_ What is your current diagnosis? \_\_\_\_\_

3) Please specify your gender:

4a) Please list all the professionals who have provided help with the problems you associate with your diagnosis

4b) Please list any current treatment you are receiving for this diagnosis (e.g. medication, counselling etc...):

5) Are you currently attending school?

Yes \_\_\_\_\_ (where?)

High school \_\_\_\_\_; Trade school \_\_\_\_\_; Community college \_\_\_\_\_; University \_\_\_\_\_;  
Other \_\_\_\_\_

No \_\_\_\_\_ (what was the last place you attended school?)

Elementary school: Graduated \_\_\_\_\_ Left early \_\_\_\_\_ (What grade)

High school (What grade) \_\_\_\_\_;

Trade school Graduated \_\_\_\_\_ Left early \_\_\_\_\_;

Community college Graduated \_\_\_\_\_ Left early \_\_\_\_\_;

University Graduated \_\_\_\_\_ Left early \_\_\_\_\_;

Other \_\_\_\_\_.

Has anyone else in your family been diagnosed with psychiatric difficulties?

\_\_\_\_ Yes

\_\_\_\_ No

If yes, who?

### DEMOGRAPHIC QUESTIONNAIRE (Parents)

My child is:

1) Your current age: \_\_\_\_\_

2) Please specify your gender:

3) Time since your child's diagnosis: \_\_\_\_\_

4a) Treatments undertaken to date:

4b) Treatments planned:

5) Your level of education:

a) Less than high school \_\_\_\_\_

b) High school (or equivalent) \_\_\_\_\_

c) Community college \_\_\_\_\_

d) University \_\_\_\_\_

e) Other \_\_\_\_\_

6) Your marital status: \_\_\_\_\_

7) Number of children: \_\_\_\_\_

Their ages: \_\_\_\_\_

8) Employment status:

9) Approximate family income:

10) Have you or anyone else in your family experienced mental health symptoms which are similar to your child's?

Yes\_\_\_\_ No\_\_\_\_

If yes, who?

11) Have you or anyone else in your family been diagnosed with a mental health issue?

Yes\_\_\_\_ No\_\_\_\_

If yes, what was the diagnosis?

**INTERVIEW GUIDES FOR STAGE II****Interview 1: Problem history interview with the family**

*To take place upon referral to CHILDREN'S HOSPITAL.*

The following interview is meant to help me understand your story about the treatment for the psychiatric diagnosis you have received/witnessed so far. The intention of the following questions is to ask about your experience of this diagnosis and the treatments that have followed. In asking these questions I am not offering an opinion on your diagnosis or the judgement of your clinicians.

1. How do you describe the problems that the [Community Agency/ Children's Hospital team] is offering you help for?

1a. [if the answer is overly vague] Given that [child's name] is being seen for a potential psychiatric diagnosis, do you think this is the best name for their difficulties? If not, how do you describe [child's name]'s difficulties?

2. When did [child's name here] experience [insert name for symptoms given by the family here] for the first time? [Substitute respondent's terms for their diagnosis in this and subsequent questions.] [Let the narrative go on as long as possible, with only simple prompting by asking, 'What happened then? And then?']

3. [If not already answered in previous question] tell me about how your family came to the [Community Agency/ Children's Hospital team].

4. Before you were referred to the [Community Agency/ Children's Hospital team] were there any professionals who helped [child's name] with the problems for which you are now seeking help?

5. Was there more than one professional (e.g. school staff, psychologist, family physician etc....) involved in your [child's name]'s care?

5a. If yes, did these professionals communicate with each other? How do you know?

5ai. Do you think these professionals agreed with each other about the causes, description and treatment of [child's name]'s difficulties? How do you know?

6. What are your hopes for the treatment you receive from the [[Community Agency]/ CHILDREN'S HOSPITAL OPD clinic] team?

6a. How will you know if the treatment you receive is meeting your expectations?

**Interview 2: Review of Collaborative Treatment Experience**

*This interview will be conducted with the whole family three months following their initial interview.*

1. Since you began with the [Community Agency/ Children's Hospital team], how much do you think the two organizations communicated?
  - 1a. What told you they were communicating?
  - 1b. Was it more or less than you expected?
  - 1c. What effect did this have on you?
2. On a scale of 1-10 (with one being not at all and 10 being always), how well coordinated was [child's name]'s care?
  - 2a. Can you tell me more about your rating?
  - 2b. Is there a particular story that you could tell me about the ways in which your care was (not) well –coordinated.
3. Did you have a treatment plan that you brought between organizations?
  - 3a. What did your treatment plan include? Do you have a copy?
  - 3b. Was this treatment plan useful? How so?
4. Did you feel that the CHILDREN'S HOSPITAL OPD clinic and the [Community Agency] staff worked together to give you choices in [child's name]'s care.
  - 4a. Could you say more about your answer? What did staff do to (not) give you choices?
5. How similar were your service providers' descriptions of [child's name]'s problems?
  - 4a. what did they say that was similar/different?
  - 4b. were you ever confused by their descriptions?
6. Since you began treatment has your understanding of [child's name]'s difficulties changed?
  - 5a. how has your understanding changed?
  - 5b. what did your clinicians say to you that has changed your understanding?
  - 5c. (if the language used was different) what was this like for you to have different words used to describe the problem?
7. Who seemed in charge of [child's name]'s treatment.
  - 7a. why do you think this particular person was in charge?

**CONSULTATION QUESTIONS FOR STAGE III (for service provider focus groups)**

*Based on the themes and the map of the ways in which children and their families experience collaborative treatment for psychiatric diagnoses that was just presented to you:*

1. What stood out for you [as a parent/ young person/ service provider]?
2. What confirmed your understandings of the experience of collaborative care?
3. What were you surprised about?
4. Did anything that was presented seem out of step with your understanding of collaborative care?
5. Was there anything that you feel needs to be included that wasn't?
6. What are you taking away from this presentation?
7. What do you hope others (i.e. policy makers, service providers, and other families) take away from learning about the experience of collaborative care for psychiatric diagnoses?

**APPENDIX C: CONSENT AND ASCENT FORMS**  
**CONSENT TO CONTACT FORM (STAGE I-PARENTS)**

Hello Parents,

My name is Noah Spector and I am a doctoral candidate at the University of Ottawa. For my research, I am working with the [Community Agency] and the [Children's Hospital] to explore some of the challenges of supporting young people with mental health difficulties and their families.

Particularly, I am interested in your views on the help you received from professionals who work at [Community Agency] and [Children's Hospital], who offered you help at different times during your treatment. I would like to know about your views on what it was like having your son/daughter served by these professionals who work in different agencies. This research is important because these professionals all have to share responsibilities in helping people with mental health difficulties: for this, they try to work together to meet the needs of young people and their families. By getting your views on your child's treatment by all of these professionals, I hope to better understand the needs of young people who have been diagnosed with mental health difficulties and their families. I also hope to get your views on what these professionals do to share care (for example, how they work together to make sure your child's treatment is moving forward).

You and your family's participation in this study would involve participating in separate focus groups (one for parents and one for young people). In these focus groups you and your child will be asked similar questions about your experiences of being helped by [Community Agency] and [Children's Hospital].

If you are interested in hearing more about this study, please provide the information below, and then give this form to the receptionist. I will then call you to tell you more and to answer any of your questions about the project.

\_\_\_\_\_  
Last name (please print)

\_\_\_\_\_  
First name (please print)

\_\_\_\_\_  
Daytime phone number

\_\_\_\_\_  
Evening phone number

If you prefer, you can leave a message for [Researcher] or email me at [email address] stating your name and your phone number. I will then call you back with more details. If you have any questions, you can also contact my supervisor: [Research Supervisor], at [contact information]

Thank you for taking the time to read this invitation.

**CONSENT TO CONTACT FORM (STAGE I-ADOLESCENTS 16 YEARS AND OLDER)**

Hello,

My name is Noah Spector and I am a doctoral student at the University of Ottawa. For my research, I am working with the [Community Agency] and the [Children's Hospital] to explore some of the challenges of supporting young people with mental health difficulties and their families.

Particularly, I am interested in your views on the help you received from professionals who work at [Community Agency] and [Children's Hospital], who offered you help at different times during the time you have been accessing services. I would like to know about your views on what it was like being served by these professionals who work in different agencies. This research is important because these professionals all have to share responsibilities in helping people with their mental health concerns; for this, they try to work together to meet the needs of young people, like you, and their families. By getting your views on being helped by all of these professionals, I hope to better understand the needs of young people who have been diagnosed with mental health difficulties and their families. I also hope to get your views on what these professionals do to share care (for example, how they work together to make sure your treatment is moving forward).

You and your family's participation in this study would involve taking part in separate focus groups (one for parents and one for young people). In these focus groups you and your parents will be asked similar questions about your experiences of being helped by [Community Agency] and [Children's Hospital].

If you are interested in hearing more about this study, please provide the information below, and then give this form to the receptionist. I will then call you to tell you more and to answer any of your questions about the project.

\_\_\_\_\_  
Last name (please print)

\_\_\_\_\_  
First name (please print)

\_\_\_\_\_  
Daytime phone number

\_\_\_\_\_  
Evening phone number

If you prefer, you can leave a message for [Researcher] or email me at [email address] stating your name and your phone number. I will then call you back with more details. If you have any questions, you can also contact my supervisor: [Research Supervisor], at [contact information]

Thank you for taking the time to read this invitation.

**STAGE I PARENT CONSENT FORM FOR PARTICIPATION****Fostering Shared Vision and Care in Pediatric Chronic Disease Management using a Web-Based Communication System; “The WeTakeCare Project”****Principal Investigator: [Children's Hospital Contact]****Sub-project:** Continuity between Professional Cultures: Inter-Professional Collaboration and Children's Mental Health

Doctoral Student: Noah Spector, M.S.W. Supervisor: Dr. David Paré, PhD, **Department of Educational Counselling, University of Ottawa**

I, \_\_\_\_\_, am aware that the purpose of this study is to investigate experiences of families such as mine who have received mental health treatment for their children. More specifically, the investigator is interested in how my family and I see cooperation (or continuity) between hospital and community based professionals when both of these professionals have provided my child with mental health treatment. I will be invited to participate in a focus group. In this group, I will be asked to talk about my experiences as a parent of a young person who received mental health specific services in as much detail as possible. I am aware that the results of this research project will be of help to other families receiving services for mental health difficulties and these families' service providers. Results of this focus group will be turned into themes to help the researcher investigate these treatment experiences in depth. These results will be used by the researcher, mental health service providers, and educators to get a better understanding of families' experiences of mental health treatment involving hospital and community services. I understand that the present study is being conducted as part of the requirements for Mr. Noah Spector's PhD degree under the supervision of Dr. David Paré of the Department of Educational Counselling at the University of Ottawa.

I agree to participate in the study and I am willing to share my experiences with the interviewer. I am aware that, as part of the data collection process, I will be asked to complete a form about my background and to participate in a 90-minute focus group with other parents of young people who have received services from the [Children's Hospital] Outpatient clinics and [Community Agency] for mental health difficulties. This focus group will be audio-recorded and analyzed by Noah Spector and his assistant(s). I understand that I will also be provided with a summary of this focus group and the themes that are the result of the analysis of this summary.

I realize that my participation in the research process is voluntary and that I can withdraw from the study at any time without penalty. If I choose to withdraw from the study, any demographic information I provide will be destroyed. However, because I will be participating in a focus group, data that I provide in the context of this group will not be destroyed. I am also aware that if discussion of my experiences raises any concern for me that I wish to discuss further with a mental health professional, Mr. Spector will suggest resources that I might contact and/or connect me with members of my clinical team. Should none of these resources meet my needs, I may contact the researcher for additional resources. In addition, I am aware that if the researcher suspects that I am a danger to myself or to others or if the researcher suspects that a child under 16 years of age is in danger, he is obligated to contact the Children's Aid Society or the appropriate authorities.

I am aware that all information associated with this study is strictly confidential and that my identity, or that of any persons that I mention, will be known only to the researcher and will not be revealed at any time. I also agree to keep the discussions I have in this focus group confidential. In order to keep my identity secret, when transcribing the interview recordings, the researcher will use pseudonyms (i.e., false names) for my name for those of any persons that I mention. The pseudonyms will also be used in writing the dissertation manuscript and any related publications or presentations. Any details in the interview recordings that might identify me or any persons that I mention will also be changed during the transcribing. Quotes might be used from my transcript but no information that can identify me will appear in these quotes. Furthermore, the researcher, research assistants and researcher's supervisor will be the only persons with access to the audiotape recordings and interview transcripts. These will be stored in a secure place for seven years after which time they will be destroyed.

I am aware that information obtained from the interview will be used by the researcher solely for the purposes outlined. I also understand that the results of this study may be disseminated through conferences and publications.

The [Children's Hospital] Research Ethics Board (REB) has reviewed and approved this research project. The REB is a committee that includes individuals from different professional backgrounds that review all research that takes place at the hospital. Its goal is to ensure the protection of the rights and welfare of people involved in research. The REB's work is not intended to replace a parent, child, or professional's judgment about what decisions and choices are best for them. I may contact the Chair of the Research Ethics Board at [Children's Hospital], for information regarding patients' rights in research studies at [Contact Information], although this person cannot provide me with any health-related information about the study. For inquiries related to my medical/ psychological treatment, I can also contact [Children's Hospital Principal Investigator, contact information], [[Community Agency] Clinical contact] or the [Children's Hospital] research coordinator of this study[Contact Information], stating my name, and phone number.

If I have any questions regarding the ethical conduct of this study, I may also contact the following persons:

| Organization and Person                                             | Contact information                                                                    |
|---------------------------------------------------------------------|----------------------------------------------------------------------------------------|
| University of Ottawa:<br>Protocol Officer for Ethics<br>in Research | Phone: 613-562-5387<br>Email: <a href="mailto:ethics@uottawa.ca">ethics@uottawa.ca</a> |
| [Children's Hospital]:<br>Patient Advocate                          | [Contact Information]                                                                  |
| [Community Agency]:<br>Director of Mental Health<br>Services        | [Contact Information]                                                                  |

I am also aware that any inquiries about the research study should be addressed to Mr. Noah Spector [Contact Information] or his supervisor Dr. David Paré, [Contact Information]

I agree to participate in the focus group that this form describes. I also consent to being audio recorded during the focus group.

---

Date

---

Signature of Participant

---

Signature of Researcher

You will be given a copy of this form to keep for yourself

**STAGE I- ADOLESCENT CONSENT FORM FOR PARTICIPATION**  
**Fostering Shared Vision and Care in Pediatric Chronic Disease Management using a**  
**Web-Based Communication System; “The WeTakeCare Project”**  
**Principal Investigator: [Children's Hospital Contact]**

**Doctoral Student: Noah Spector, M.S.W. Supervisor: Dr. David Paré, PhD, Department of**  
**Educational Counselling, University of Ottawa**

**Purpose of this research study**

You are invited to take part in a study that is being conducted by me, Noah Spector, a PhD student from the University of Ottawa who works with the [Children’s Hospital] and the [Community Agency]. I hope to use what I find in this study to help mental health professionals cooperate (or to provide continuous services) to give young people such as you so that they receive the best treatment possible. The goal of the study is to document your experiences of mental health professionals trying to cooperate to help you and how their cooperation, with you and each other, affects your family’s daily life.

The specific objective of this research is to describe young people and their families’ experiences of being treated by many different healthcare providers for mental health difficulties.

**Procedures**

The first step in this research will be a focus group with veterans of mental health treatment. By veterans, I mean young people like you, who are 16 years of age or older and have already received some mental health treatment. I am inviting you to participate in a focus group through the [Children’s Hospital] outpatient clinic (OPD) or the Youth Services Bureau of Ottawa ([Community Agency]). This focus group will address how young people like you and their parents have experienced different professionals cooperating to provide care for problems associated with mental health difficulties.

**Focus Groups**

I will collect information in this focus group by asking you to fill out a short questionnaire about your background as well as through asking the group to discuss some questions. These questions will be about your views on mental health treatment as well as your experiences of various professionals cooperating to provide this treatment. There will be four to five participants per group, and the focus group session will last approximately 90 minutes. What is said during the focus group will be recorded and later analyzed by a group of researchers.

**Your options**

It is completely up to you to choose to participate in this focus group. Nothing about your treatment will change if you choose not to participate. You can also decide to not take part in the focus group at any time. If you are uncomfortable with any topics or discussions, you can choose not to participate in the discussion.

**Are there any risks to participating in the research?**

The purpose of the methods used in this study is to collect information. Given that you will guide the process, there is a minimal level of risk and discomfort.

Some participants may feel uncomfortable sharing their experiences. To help you feel comfortable, the participants will be grouped into focus groups with people like them (i.e., a parents group and a youth group). In this way, I will try to make sure that you can speak freely without being scared of what an adult, like a parent or a doctor, might think of what you are saying.

**Benefits**

By helping out with this research study, you will contribute to a better understanding of the needs of young people like you so that mental health workers can learn how to cooperate with each other to help you in the best way possible.

**Limits of confidentiality**

Your personal information will be kept strictly confidential, except as required or permitted by law. If I suspect that you may be a danger to yourself or to others or possible child abuse or neglect of a child under 16 years of age is taking place, I must work with my supervisor and other professionals (e.g., CAS or the police) to make sure you or anyone else is safe.

Any information collected from you will be locked in a safe location and only researchers involved with this project will have access to this information. You will not be identified in any publication or presentation of this study. There are two copies of this consent form, one that the researchers keep, and one for you to keep. A summary of the general results of this study will be sent to all participants and the results of this study (with all identifying information removed) will be shared at conferences and with people from [Community Agency] and [Children's Hospital].

The [Children's Hospital] Research Ethics Board (REB) and the University of Ottawa REB have reviewed and approved this research project. REBs are committees that include individuals from different professional backgrounds that review all research that takes place at the hospital. Their goal is to make sure that the rights and welfare of people involved in research are protected. REBs' work is not intended to replace a parent, child, or professional's judgment about what decisions and choices are best for them. You may contact the Chair of the Research Ethics Board at [Children's Hospital], for information regarding patients' rights in research studies at [Contact information], although this person cannot provide me with any health-related information about the study. For inquiries related to my medical/ psychological treatment, you can also contact [Children's Hospital Principal Investigator, contact information], [clinical contact at [Community Agency]] or the [Children's Hospital] research coordinator of this study: [Contact Information], stating your name, and phone number.

If you need to talk to someone about how you were treated in the study, you can also contact these people:

| Organization and Person                                             | Contact information                                                                    |
|---------------------------------------------------------------------|----------------------------------------------------------------------------------------|
| University of Ottawa:<br>Protocol Officer for Ethics<br>in Research | Phone: 613-562-5387<br>Email: <a href="mailto:ethics@uottawa.ca">ethics@uottawa.ca</a> |
| [Children's Hospital]:<br>Patient Advocate                          | [Contact Information]                                                                  |
| [Community Agency]:<br>Director of Mental Health<br>Services        | [Contact Information]                                                                  |

I am also aware that any inquiries about the research study should be addressed to Mr. Noah Spector [Contact Information] or his supervisor Dr. David Paré, [Contact Information]

I give my consent to participate in this study looking at how mental health professionals cooperate. I agree to participate in a focus group and be audio recorded during this group. I will also keep everything I hear in this group confidential.

\_\_\_\_\_  
Last Name (please print)

\_\_\_\_\_  
First Name (please print)

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

You will be given a copy of this form to keep for yourself.

**CONSENT TO CONTACT FORM (STAGE II PARENTS)**

Dear Parents,

I am a PhD student at the University of Ottawa who is working in collaboration with the [Community Agency] and the [Children's Hospital] to investigate the challenges of offering children mental health treatment. We think that some of the challenges result from the involvement of many professionals (i.e. pediatricians, psychologists, social workers, psychiatrists, parents, and teachers), each possibly working at different locations, seeing the child at different times and asking different questions. However, these professionals all have to share the care for children with mental health difficulties: for this, they try to work together to meet the needs of the children and their families in the care of these professionals. By working with all of these professionals, we hope to better understand the needs of children who are receiving treatment and their families, and to hear your views on how these professionals currently share care (for example, how they work together to make sure your child's treatment is moving forward).

Your family's participation in this study would involve sharing your experiences through a series of two interviews over the course of your treatment. In these interviews, I will ask you about how you came to be treated at [Children's Hospital] and [Community Agency], and ask you to reflect back upon your experience of the treatment offered by these two organizations in three months after your first interview. Your family will be compensated for your time with \$50 for each interview you begin.

If you are interested in hearing more about this study, please provide the information below, and then give this form to the secretary. I will then call you to tell you more and to answer any of your questions about the project.

Parent/ Guardian's

\_\_\_\_\_  
Last name (please print)

\_\_\_\_\_  
First name (please print)

\_\_\_\_\_  
Daytime phone number

\_\_\_\_\_  
Evening phone number

If you prefer, you can contact me, Noah Spector directly at [\[Contact Information\]](#) . If you contact me in this way, please send me your phone number and I will get back to you ASAP.

Noah Spector, M.S.W., Ph.D. Candidate, University of Ottawa, Faculty of Education

Thank you for taking the time to read this invitation.

**STAGE II PARENT CONSENT FORM FOR PARTICIPATION**  
**Fostering Shared Vision and Care in Pediatric Chronic Disease Management using a**  
**Web-Based Communication System; “The WeTakeCare Project”**  
**Principal Investigator: [Children's Hospital Contact]**

**Doctoral Student: Noah Spector, M.S.W. Supervisor: Dr. David Paré, PhD, Department of**  
**Educational Counselling, University of Ottawa**

I, \_\_\_\_\_, am aware that the purpose of this study is to investigate experiences of families such as mine who have received mental health treatment for their children. More specifically, the investigator is interested in how my family and I see cooperation (or continuity) between hospital and community based professionals when both of these professionals have provided my child with mental health treatment. Through two interviews, I will be asked to reflect upon my experiences of my child's mental health treatment as a parent of a young person receiving mental health specific services in as much detail as possible. I am aware that this research project will be of benefit to other families receiving services for mental health difficulties and their service providers. Results of this research will help the researcher, mental health service providers, and educators get a better understanding of families' experiences of mental health treatment involving hospital and community services. I understand that the present study is being conducted as part of the requirements for Mr. Noah Spector's PhD degree under the supervision of Dr. David Paré of the Department of Educational Counselling at the University of Ottawa.

I agree to participate in the study and I am willing to share my experiences with the interviewer. I am aware that, as part of the data collection process, the following will occur:

1. My family and I will participate in a 90-minute audio taped interview about the history of my child's mental health difficulties and our pathways to [[Community Agency]/ the [Children's Hospital] Outpatient department (OPD)]
2. At the end of a three-month period after the initial interview, my family and I will take part in a final 90-minute interview about our experiences of cooperation between community and hospital based services for our child's mental health treatment in the three months between these two interviews.
3. My family and I will then be approached for our consent to participate in a telephone consultation regarding the results of this research. This consultation will happen a week after my family and I are provided with a summary of the researcher's results.
4. For each interview/consultation my family begins we will be compensated \$50 for our participation.

All interviews will be audio taped and transcribed for later analysis. I understand that the researcher will share transcripts and a summary of these interviews with me to review and correct as I see fit. I realize that my participation in the research process is voluntary and that I can stop participating in the study at any time without penalty and my family will be compensated for any interviews we begin. If I choose to leave this study, the researcher will destroy any information about me or any data, which I have provided, right away. I am also aware that if I am upset by the discussion of my experiences and I wish to discuss further with a

mental health professional, Mr. Spector will suggest resources that I might contact and/ or connect me with members of my clinical team. Should none of these resources meet my needs, I may contact the researcher for additional resources. I am also aware that if the researcher suspects that I am a danger to myself or to others or if the researcher suspects that a child under 16 years of age is in danger, he is obligated to contact the necessary authorities for example the Children's Aid Society or the Police.

I also know that all information, which I share in this study, is strictly confidential and that my identity, or that of any people that I mention, will be known only to the researcher and will not be revealed at any time. When transcribing the interview recordings, the researcher will use pseudonyms (i.e., false names) for my name for those of any persons that I mention. The pseudonyms will also be used in writing the dissertation manuscript and any related publications or presentations. Any details in the interview recordings that might identify me or any persons that I mention will also be changed during the transcribing. Quotes may be used from my transcript; however, no information that can identify me will appear in these quotes. In addition, the researcher, his assistants and researcher's supervisor will be the only persons with access to the audiotape recordings and interview transcripts. These will be stored in a secure place for seven years after which time they will be destroyed.

I am aware that the researcher will only use information obtained from these interviews for this study. I also understand that the results of this study may be used for articles, conference presentations and summaries to the organizations involved in this study.

The [Children's Hospital] Research Ethics Board (REB), the University of Ottawa REB and the [Community Agency] Research Ethics Committee have reviewed and approved this research project. These REBs/Committees include individuals from different professional backgrounds that review all research that takes place at the hospital and other settings. The goal of these REBs/Committees is to ensure the protection of the rights and welfare of people involved in research. The REB/Committee's work is not intended to replace a parent, child, or professional's judgment about what decisions and choices are best for them. Because of this, I may contact the Chair of the Research Ethics Board at [Children's Hospital], for information regarding patients' rights in research studies at [Contact information], although this person cannot provide me with any health-related information about the study. For inquiries related to my medical/ psychological treatment, I can also contact Dr. Philippe Robaey, at (613) 738-6990, extension 231, [Clinical contact at [Community Agency]] or the [Children's Hospital] research coordinator of this study: [Contact Information], stating my name, and phone number.

If I have any questions regarding the ethical conduct of this study, I may also contact the following persons:

| Organization and Person                                             | Contact information                                                                    |
|---------------------------------------------------------------------|----------------------------------------------------------------------------------------|
| University of Ottawa:<br>Protocol Officer for Ethics<br>in Research | Phone: 613-562-5387<br>Email: <a href="mailto:ethics@uottawa.ca">ethics@uottawa.ca</a> |
| [Children's Hospital]:<br>Patient Advocate                          | [Contact information]                                                                  |
| [Community Agency] :                                                | [Contact Information]                                                                  |

|                                       |  |
|---------------------------------------|--|
| Director of Mental Health<br>Services |  |
|---------------------------------------|--|

I am also aware that any inquiries about the research study should be addressed to Mr. Noah Spector [ Contact Information] or his supervisor Dr. David Paré, (613) 562-5800 ext. 4039, [Contact Information].

I agree to participate in this research. I also agree to be audio taped during the two interviews described above.

---

Date

---

Signature of Participant

---

Signature of Researcher

You will be given a copy of this form to keep for yourself.

**STAGE II ASSENT FORM FOR CHILD PARTICIPANTS (AGES 12-14-IN DEPTH INTERVIEWS)  
Fostering Shared Vision and Care in Pediatric Chronic Disease Management using a  
Web-Based Communication System; “The WeTakeCare Project”**

**Principal Investigator: [Children's Hospital Contact]**

**Sub-project: Continuity between Professional Cultures: Inter-Professional Collaboration  
and Children's Mental Health**

**Doctoral Student: Noah Spector, M.S.W. Supervisor: Dr. David Paré, PhD, Department of  
Educational Counselling, University of Ottawa**

**Purpose of this research study**

You are invited to take part in a study that is being conducted by me, Noah Spector, a PhD student at the University of Ottawa together with researchers from the [Children's Hospital] and in collaboration with the [Community Agency]. You have probably done research at school, so you already know a little bit about how it works. The goal of this study is to learn about how to help you, your family, your doctors, your workers and your teachers work together to help you with your mental health difficulties. Sometimes there are many different people trying to help you (doctors, psychologists, social workers, parents and teachers), and we think that it is important for all these people to work together. While the end goal of the study is to create a website to help keep track of everyone trying to help you, I am simply interested in your experiences of the way the system works now.

**What will I be asked to do?**

If you decide to be in this study, you and your family will be asked to participate in two interviews. If you and your family agree to participate, I will:

(1) Interview you and your family about how you came to [the [Children's Hospital] OPD/ [Community Agency]]. During this 90-minute interview I will ask about the history of the behavior and feelings you are being treated for and your previous contacts with professionals (e.g. school, family doctor, community services etc....) regarding these behaviors and feelings.

(2) Interview you and your family a final time for approximately 90 minutes at the end of a three-month period. At this time, I will ask you to tell me how you felt about your meetings with clinical staff over the past three months.

(3) I will then give you and your parents the choice to give me feedback on my how I wrote about what you and your parents told me. I will do this by sending you a copy of what I have written about you and your parents' story as well as the stories of others. I will then call you and your family a week after I give you a copy of this story and ask you for your comments on

what I have written. You and your parents' comments on this story will be included in my final project and, in combination with my results; these comments (with identifying information removed) will be shared with the staff to help them understand what worked and did not work about the help they offered to you and your family.

(4) Your family will be given \$50 for each interview you begin.

**What if I have questions?**

If you had any questions about the study or what you would be asked to do, you can call the Study Coordinator,. You can also email me, Noah Spector at [Contact Information]

**Will the study help me?**

During these interviews, if we find out something that could help you, we will talk about it together with your parents and help them to find someone to help you. In addition, what you

tell us will help families, doctors and teachers learn how to work together to help children with mental health difficulties.

**Will being in the study cause any problems for me?**

There should not be any problems and we hope that you will enjoy coming to the clinic to meet with me. If you need to take a break during the meeting, all you have to do is tell me. Also, if you are uncomfortable with any topics or discussions, you can choose not to answer the question. If at any time you do not want the meeting to be recorded, you can tell me to turn the recorder off. In this case, I will take notes about what you said instead.

**Who will know about the things I tell you?**

Everything you say will be kept private, and will be safely locked up, and nobody will know who you are except the people doing the research. Your name will be taken off all paper and you will be given a numerical code instead. If I think that you have a serious problem that will affect you or other people, I will have to talk about it with your parents. If I learn that a child is being hurt, or is at risk of being hurt, or could hurt someone else, I will have to get help from the Children's Aid Society or the police.

The [Children's Hospital] Research Ethics Board (REB), the University of Ottawa REB and the [Community Agency] Research Ethics committee have reviewed and approved this research project and they can have access to your information. These REBs/committees are groups of people that review all research that takes place at the hospital and other places. REBs make sure that people involved with research are kept safe. If you wanted to talk to someone from the REB, you could call Dr. Carole Gentile at [Contact information]. You can also call [Children's Hospital Principal Investigator, contact information] if you have any questions. If you prefer, you can also leave a message for the research coordinator, Jennifer Munroe at 613-738-6990 ext. 236, and she will call you back.

You can also call these people who are also responsible for making sure people in research are kept safe:

| Organization and Person                                             | Contact information                                                                    |
|---------------------------------------------------------------------|----------------------------------------------------------------------------------------|
| University of Ottawa:<br>Protocol Officer for Ethics<br>in Research | Phone: 613-562-5387<br>Email: <a href="mailto:ethics@uottawa.ca">ethics@uottawa.ca</a> |
| [Children's Hospital]:<br>Patient Advocate                          | [Contact Information]                                                                  |
| [Community Agency]:<br>Director of Mental Health<br>Services        | [Contact Information]                                                                  |

**Do I have to be in this study?**

You do not have to be in this study if you do not want to be. If you decide that you do not want to be in the study after we begin, you just need to tell me. If you prefer not to have the interview recorded, you can tell me and I will make the necessary arrangements.

I give my consent to participate in this study. I also agree to be audio taped during the interviews I read about in this form.

\_\_\_\_\_  
Last Name (please print)

\_\_\_\_\_  
First Name (please print)

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

You will be given a copy of this form to keep for yourself.

**Phase 3--Consent Form for Stakeholder Participants – Brief Consultation  
Fostering Shared Vision and Care in Pediatric Chronic Disease Management using a  
Web-Based Communication System; “The WeTakeCare Project”  
Principal Investigator: [Children’s Hospital Contact]  
Sub-project: Continuity between Professional Cultures: Inter-Professional Collaboration  
and Children’s Mental Health**

**Doctoral Student: Noah Spector, M.S.W. Supervisor: Dr. David Paré, PhD, Department of  
Educational Counselling, University of Ottawa**

**Purpose of this research study**

You are invited to take part in a study that is being conducted by me, Noah Spector, a PhD student from the University of Ottawa I am working in collaboration with the [Children’s Hospital]and the [Community Agency]. Using the results of the study I hope to address the challenges in systems serving young people with long term difficulties. These challenges stem from the involvement of many different partners, each with different mandates, locations, schedules, agendas, and priorities. This inevitably leads to a large amount of information about treatment being directed at the families of young people who are being treated. I am asking for the help of professionals such as yourself to validate the results of my research based on your existing clinical experiences. By working with all of these professionals, I hope to better understand the needs of children undergoing mental health treatment and their families, and to better understand the views of these families on how professionals share care to move these families’ children’s treatment forward.

**Procedures: Brief consultations**

I will conduct a brief consultation during one of your team meetings. Separate consultations will be held with families who are current clients, mental health workers based in the community and hospital based mental health workers. Your consultation will be held during one of your regularly scheduled team meeting and will be based on an accessible summary of study results which you will receive a week prior to this meeting and will last approximately 20-30 minutes. I will conduct these consultations, and will audio record my conversation with your team so that discrepancies can be resolved. Consultations will be held during your usual team meeting. Pizza will be provided as compensation for your time and feedback.

**Your options**

Your participation is voluntary and you may choose not to participate or to withdraw at any time without penalty. If you are uncomfortable with any topics or discussions, you can choose not to participate in the discussion. However, because you will be participating in a group, data that you provide in the context of this group will not be destroyed.

**Are there any risks to participating in the research?**

Given that, the participants will guide these consultations; this process involves a minimal level of risk and discomfort. As the researcher, it is my job to make sure that all participants feel comfortable during the group discussion. However, some participants may feel uncomfortable sharing their experiences. If you feel uncomfortable with any of the discussions, you can tell me and choose not to participate. To help you feel comfortable, the information collected will be kept confidential.

**Benefits**

Your participation in this research study will help to clarify the needs of children with mental health difficulties. This information will contribute to a broader project to create a computer based system that allows all those involved in the child's care to communicate with each other more effectively and move ahead with a united plan to address the needs of the child.

### **Limits of confidentiality**

Your personal information will be kept strictly confidential, except as required or permitted by law. As well, the [Children's Hospital] Research Ethics Board can have access to your personal information. Health professionals are required by law to report any suspicion of child abuse. If the researchers suspect possible child abuse or neglect, based on the observations or responses of participants during the focus groups, (s) he will contact Dr. Robaey who will be on call during research appointments. Any other information will be treated with the greatest respect for your privacy.

In order to protect your privacy, your name will be replaced on all forms and records by a number code. Any information collected will be locked in the researchers' lab, and only researchers involved with this project will have access to them. When stored in a computer system, the information will be password protected and kept on a secure system at [Children's Hospital]. All research records will be retained for a minimum of 7 years after the study closure. You will not be identified in any publication or presentation of this study. There are two copies of this consent form, one that the researchers keep, and one for you to keep. Upon request, a summary of the general results of this study will be sent to you.

The [Children's Hospital] and University of Ottawa Research Ethics Boards (REBs) as well as [Community Agency]'s Ethics Committee have reviewed and approved this research project. These REBs/committees are groups that include individuals from different professional backgrounds that review all research which takes place at hospitals and other sites. Their goal is to ensure the protection of the rights and welfare of people involved in research. These groups' work is not intended to replace a parent, child, or professional's judgment about what decisions and choices are best for them. You may contact, the Chair of the Research Ethics Board at [Children's Hospital], for information regarding patients' rights in research studies at [Contact information], although this person cannot provide any health-related information about the study. Please feel also free to contact [Children's Hospital Principal Investigator, contact information] if you have any remaining questions. If you prefer, you can also leave a message for the research coordinator of this study: [Contact information], stating your name, and your phone number. She will call you back with additional details.

If you need to get in touch with additional people regarding the ethical contact of the researcher you can also contact the following representatives at each organization:

| Organization and Person                                             | Contact information                                                                    |
|---------------------------------------------------------------------|----------------------------------------------------------------------------------------|
| University of Ottawa:<br>Protocol Officer for Ethics<br>in Research | Phone: 613-562-5387<br>Email: <a href="mailto:ethics@uottawa.ca">ethics@uottawa.ca</a> |
| [Children's Hospital]:<br>Patient Advocate                          | [Contact Information]                                                                  |
| [Community Agency]:<br>Director of Mental Health<br>Services        | [Contact Information]                                                                  |

I give my consent to participate in this study, which is hoping to clarify and address the challenges of serving children with mental health difficulties. I agree to be audio taped during the brief consultation.

---

Last Name (please print)

---

First Name (please print)

---

Signature of Participant

---

Date

You will be given a copy of this form to keep for yourself.

**Phase 3--Consent Form for family Participants – Telephone Consultation  
Fostering Shared Vision and Care in Pediatric Chronic Disease Management using a  
Web-Based Communication System; “The WeTakeCare Project”  
Principal Investigator: [Children's Hospital Contact]  
Sub-project: Continuity between Professional Cultures: Inter-Professional Collaboration  
and Children’s Mental Health**

**Doctoral Student: Noah Spector, M.S.W. Supervisor: Dr. David Paré, PhD, Department of  
Educational Counselling, University of Ottawa**

**Purpose of this research study**

You are invited to take part in a study that is being conducted by me, Noah Spector, a PhD student from the University of Ottawa who works in collaboration with the [Children’s Hospital]and the [Community Agency]. I hope to use what I find in this study to help mental health professionals cooperate (or to provide continuous services) to give young people and their families the best treatment possible. The specific objective of this research is to describe young people and their families’ experiences of being treated by many different healthcare providers for mental health difficulties.

I am asking your help to comment on the results of my research based on my interactions with you over the past three months. By getting your comments on my results, I hope to make sure that you are able to comment on the stories I will be telling about your experiences. I will use these stories and your comments to talk about the needs of children with mental health difficulties and their families and to make sure that the feedback I give to these professionals reflects your views on how professionals currently share care to make sure your child’s treatment is moving forward.

**Procedures: Telephone Consultation**

I will conduct a telephone consultation with you and your family concerning the results of my research. This consultation will be held following the completion of my data collection regarding families’ experiences of collaborative care. I will provide you with an easy to read summary of my research results and then follow-up with a phone call a week after I provide you with this summary. Separate consultations will be held for families who are current clients, mental health workers based in the community and hospital based mental health workers. I will conduct this consultation and it will be audio recorded so that discrepancies can be resolved. This telephone consultation will be scheduled at a convenient time for your family. You will be compensated with \$50 if you begin this consultation.

**Your options**

Your participation is voluntary and you may choose not to participate or to withdraw at any time without penalty. If you are uncomfortable with any topics or discussions, you can choose not to participate in the discussion. If you choose not to complete this consultation any information you provide will be destroyed and you will be able to keep your compensation for your participation.

Are there any risks to participating in the research?

Given that you will guide the consultation; this process involves a minimal level of risk and discomfort. As the researcher, it is my job to make sure that all you and your family feels comfortable during this discussion. However, sometimes people feel uncomfortable sharing their

experiences. If you feel uncomfortable with the consultation, you can tell me and choose not to participate. To help you feel comfortable, the information collected will be kept confidential.

### **Benefits**

Your participation in this research study will help to clarify the needs of children undergoing mental health treatment. This information will contribute to a broader project to create a computer-based system that allows all those involved in the child's care to communicate with each other more effectively and move ahead with a united plan to address the needs of the child.

### **Limits of confidentiality**

Your personal information will be kept strictly confidential, except as required or permitted by law. As well, the [Children's Hospital] Research Ethics Board can have access to your personal information. Health professionals are required by law to report any suspicion of child abuse. If the researchers suspect possible child abuse or neglect, based on the observations or responses of participants during the focus groups, (s) he will contact Dr. Robaey who will be on call during research appointments. Any other information will be treated with the greatest respect for your privacy.

In order to protect your privacy, your name will be replaced on all forms and records by a number code. Any information collected will be locked in the researchers' lab, and only researchers involved with this project will have access to them. When stored in a computer system, the information will be password protected and kept on a secure system at [Children's Hospital]. All research records will be retained for a minimum of 7 years after the study closure. You will not be identified in any publication or presentation of this study. There are two copies of this consent form, one that the researchers keep, and one for you to keep. Upon request, a summary of the general results of this study will be sent to you.

The [Children's Hospital] Research Ethics Board (REB), the University of Ottawa REB and the [Community Agency] Ethics Committee have reviewed and approved this research project and [Community Agency] also reviewed and approved the research project. These REBs/committees include individuals from different professional backgrounds that review all research that takes place at the hospital and other sites. The goal of these groups is to ensure the protection of the rights and welfare of people involved in research. The work of these groups is not intended to replace a parent, child, or professional's judgment about what decisions and choices are best for them. You may contact the Chair of the Research Ethics Board at [Children's Hospital], for information regarding patients' rights in research studies at [Contact information], although this person cannot provide any health-related information about the study. Please feel also free to contact [Children's Hospital Principal Investigator, contact information] [or [Community Agency] clinical contact] if you have any remaining questions. If you prefer, you can also leave a message for the research coordinator of this study:, stating your name, and your phone number. She will call you back with additional details.

You can also contact the following people if you have concerns about the ethical conduct of the researcher:

| Organization and Person                                             | Contact information                                                                    |
|---------------------------------------------------------------------|----------------------------------------------------------------------------------------|
| University of Ottawa:<br>Protocol Officer for Ethics<br>in Research | Phone: 613-562-5387<br>Email: <a href="mailto:ethics@uottawa.ca">ethics@uottawa.ca</a> |
| [Children's Hospital]:<br>Patient Advocate                          | [Contact Information]                                                                  |

|                                                              |                       |
|--------------------------------------------------------------|-----------------------|
| [Community Agency]:<br>Director of Mental Health<br>Services | [Contact Information] |
|--------------------------------------------------------------|-----------------------|

I give my consent to participate in this study, which is hoping to clarify and address the challenges of offering children mental health treatment. I agree to my family being audiotaped during the telephone consultation.

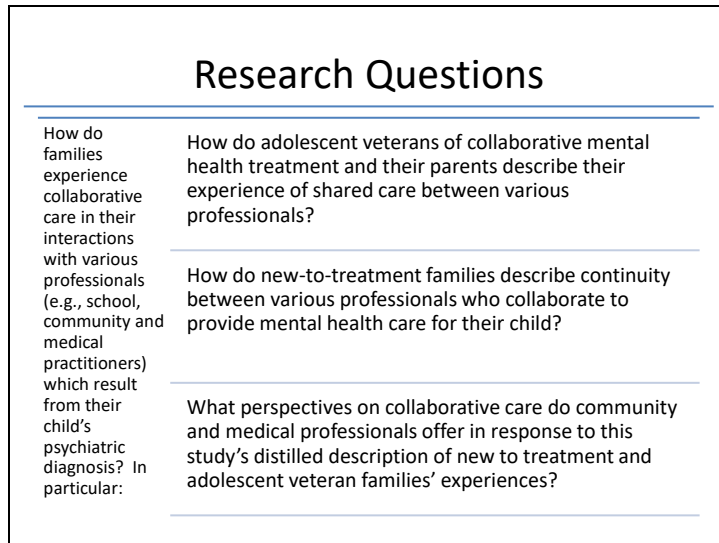
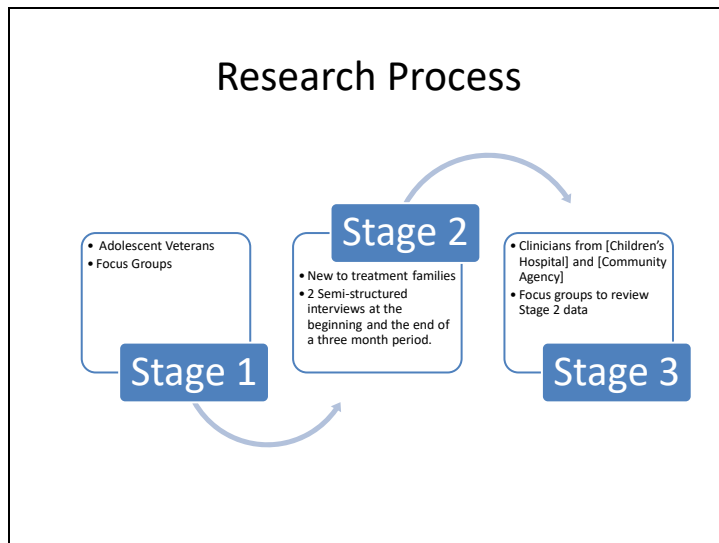
\_\_\_\_\_  
Last Name (please print)

\_\_\_\_\_  
First Name (please print)

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

You will be given a copy of this form to keep for yourself.

**APPENDIX D: SELECTED RECRUITMENT PRESENTATION SLIDES****Slide 1: Research Questions****Slide 2: Research Process**

**Slide 3: Recruitment Criteria, Stage 1****Sample: Stage 1 Theme Generation**

- Stage 1: 5 Adolescent veterans of collaborative mental health treatment and their families
  - **Eligibility Criteria:**
    - Between 16-19 years of age
    - At least six months of previous contact with either the [Community Agency] or the [Children's Hospital] OPD clinics and some contact with the other organization.
    - No significant psychotic symptoms.
    - Able to read English at a 5<sup>th</sup> grade level.

**Slide 4: Recruitment Criteria, Stage 2****Stage 2 Fieldwork: Sample**

- **4 new to treatment families referred:**
  - From the [Children's Hospital] outpatient psychiatric clinics to [Community Agency] services, OR
  - From [Community Agency] services, via family MD, to [Children's Hospital]'s outpatient psychiatric clinics

**\*Families will be paid \$50 per interview\***
- **Eligibility Criteria:**
  - Child diagnosed mental health difficulties and at least 12 and not older than 16 years of age
  - No significant, ongoing psychotic symptoms.
  - Willingness & ability to participate in 2 family interviews over 3 mos.
  - Able to read English at a 5<sup>th</sup> grade level.

**\* Looking for 2 male and 2 female youth\***

**APPENDIX E: PARENT FOCUS GROUP SUMMARY**

1. How do families experience collaborative care in their interactions with various professionals (e.g., school, community and medical practitioners) that result from their child's psychiatric diagnosis? In particular:
  - a) How do adolescent veterans of collaborative mental health treatment and their parents describe their experience of shared care between various professionals?

**Procedures and participants**

Three mothers attended this focus group. These mothers will be referred to in reference to their kids (i.e., PP3 will be the mother of P3 etc.). Two were parents of male youth and one was the parent of a female youth. The data for this group also involves two emails sent by one of the participants afterwards. The researcher facilitated the group and two RAs were present to take notes. The group lasted approximately an hour and thirty minutes. Pizza and soft drinks were provided.

**Summary of Group Content:**

In response to the question of what brought them to seek help from their service providers, PP3 began by describing how P3 had been quite restless in daycare and how he had difficulties making friends. P3's actions continued to be concerning to his teachers and PP3 recalls that a teacher in one of his kindergarten classes thought P3 might have ADHD. PP1 described how P1 had expressed that he was depressed and suicidal around grade 8 or 9. She recalls initially bringing her son to the local children's hospital emergency room and being given resources. PP1 identified their second visit to the local children's hospital as the beginning of she and her son's long journey. PP4 reported two points of entry to the system for her daughter. The first was in kindergarten/ pre-kindergarten when her daughter had difficulties with speech and was diagnosed with a learning disability in reading and writing. PP4 recalled that following supports being put in place for her daughter in school a second incident resulting in her daughter's suspension from school in grade 8. PP4 went on to describe the journey of helping her daughter as lasting four years to the present time in grade 11 when her daughter was expelled from one school to go to an alternative school and a psychiatric assessment was recommended.

The parents had different experiences of their child being given a psychiatric diagnosis with PP4 saying that her daughter had not been given an official diagnosis despite assessments from several mental health professionals. PP1 recalled that her son had been given multiple

diagnoses following his in-patient treatment. These diagnoses included Major Depression, Anxiety and ADHD. PP1 recalled that the process of understanding her son's diagnosis took approximately 2 1/2 to 3 years. PP1 however remarked that despite the different agencies involved, her son has had a consistent diagnosis of depression. PP4 described how she and her daughter remained in the process of trying to figure out what was wrong. PP4 recalled that a massive change occurred for her daughter in grade 8 and that since her family and her daughter have been on a journey of mental health treatment without a coherent direction. PP3 described the story of her son as quite straightforward and that, even though the professionals suspected Asperger's syndrome at one point, there was a quick consensus that her son suffered from ADHD. While PP3 felt that her son's earlier problems were mostly resolved PP1 and PP4 described themselves as still in the process.

When asked if the diagnoses that their children were given reflected the things they were concerned about the participants went against the assumption of a static diagnosis to a description of their children and their children's concerns as constantly evolving. In addition, PP1 and PP3 who described their children as having complex and on-going mental health difficulties described their wish for more holistic approaches to their children's treatment. The parents described their feelings of being constantly surprised by the new challenges their children continue to face as well as the multiple service providers that their children must speak to. PP3 presented a different story in which her child's diagnosis (ADHD) prompted a clear path of treatment in which consistent psychiatric intervention resulted in a resolution of symptoms. In contrast, PP4 spoke about her feelings of frustration that P4 was shut out of services due to not being suicidal. PP4 described feeling frustrated at getting her daughter into the system due to the fact that the things which were concerning to the family (e.g., cutting and running away) were not seen as serious enough by the professionals and resulted in a delayed entry to the system.

When asked if anything changed after they received a diagnosis for their child, the participants appeared unclear about a demarcation of before and after the diagnosis in the story of their child. PP4 emphasized her experience of not receiving a clear diagnosis for her child and her feelings that, despite descriptions of her child's difficulties as depression, her daughter's struggles had not been adequately described. PP4 emphasized her feeling that the inadequacy of the descriptions of P4's difficulties by clinical staff had led to inadequate treatment interventions. For example, PP4 mentioned how she suspected that the school had moderated P4's assessment

in order not to offer additional supports. PP4 emphasized her desire for someone to help parents get through the system and agreed with the investigator's suggestion of navigator as a term to describe the role of this person. What PP4 described as this person's role would be 24-hour support to families to access proper mental health services. PP4 cited an ideal model for this kind of service that is currently offered in BC. She sent the investigator a description of this service (see Appendix). PP1 described how with P1 the point of diagnosis did not change much. She described her experience of her son being hospitalized at the local children's hospital and her subsequently being unable to access a large assessment when P1 had turned 16. Overall, PP1 expressed her feeling that she had not heard the whole story about P1 due to confidentiality and how she perceived this contributing to P1's tendency to tell different service providers and parents different aspects of his story. She described her feelings that everyone in the system is doing their best but that the overall experience is incongruent. PP4 spoke up at this point to describe how young people in the system are often asked to tell their stories to many different professionals and the difficulties in these professionals communicating with each other and communicating with parents. PP3 described her relief in the news that P3 was diagnosed with "just ADHD" but also her frustration with the long wait for an assessment in the public sector and the harm she witnessed this wait had for P3 who she perceived was quite misunderstood by his school staff during the wait for an assessment.

The parents agreed that wait-times for mental health services are difficult to understand given the fact that children change dramatically over a short period of time. PP4 gave an example of how she felt that being unable to see P4's assessment due to confidentiality concerns led to her not advocating as strongly as she could have for more intensive services for P4. PP4 expressed her frustration that services appeared siloed and unable to work towards a similar goal. She cited her frustration that this may be due to funding concerns. PP4 described her frustration with people studying the system and not seeing very much change in her experience of P4's treatment. When PP1 questioned why services were not talking to each other, PP4 mentioned the service wraparound as a helpful service that was able to coordinate interventions. PP4 added the caveat that P4 had to sign consents for information to be shared.

When asked about who helped with the problems associated with their child's diagnosis, PP4 expressed her feeling of being her child's primary service provider. PP4 also expressed her appreciation for the local substance use counselling agency. In particular, PP4 cited the provision

of a counsellor for the parents in addition to their child's counsellor as a very helpful part of this agency's interventions with her family. She described a decision point in which she was considering sending P4 to a residential treatment facility and how a police officer friend had assisted her in reconsidering this choice. PP4 also cited this friend as being key to getting P4 into treatment following this family friend's recognition that P4 was involved with persons who were involved in drugs and his subsequent advocacy to get P4 into the substance-use counselling agency. In reflecting on this aspect of her family's story PP4 expressed her wish that the local children's hospital had been more insistent on providing comprehensive treatment to P4 early on and PP4's feeling that more intensive treatment earlier on may have mitigated some of her child's later problems. PP1 described how she had to be a strong advocate for P1 due to her experience of the local children's hospital's emergency department as trying to get families in and out as quickly as possible. She especially cited the local children's hospital's high threshold before intervening (i.e., even if you're suicidal you may not get in). PP1 spoke about her appreciation that a particular psychiatrist recommended that P1 be treated at the local mental health hospital. PP1 emphasized that this one psychiatrist had been particularly concerned about the means that P1 took in his suicide attempt and the importance of this psychiatrist's advocacy efforts. Both PP1 and PP4 agreed that they experienced it as particularly helpful when a service provider (or helper) took their child's difficulties and their appreciation that these helpers emphasized the seriousness of the situation. PP3 added that she felt quite pleased by a particular outpatient service at the local children's hospital and satisfaction with the service providers within this service. She also emphasized her appreciation of the local youth counselling agency in she and P3 being able to talk to staff at this agency when she and P3 were experiencing difficulties in their relationship. PP4 also spoke about her experience of the local youth counselling agency. In particular, PP4 described a negative experience of being denied particular services by this agency as she suspected that the agency staff felt that her family was well supported by other services within this agency in addition to another agency and a private psychotherapist. PP4 then described how following a number of structural barriers (e.g., job loss) which made the use of a private psychotherapist impossible her family was again denied access to this particular service (MST) because they had previously accessed other services within the community youth counselling agency. PP4 expressed her frustration that it felt at the time that the community youth counselling agency was enacting additional barriers to access the service

that she believed P4 needed. PP1 agreed with PP4 when asked that much of their frustration when receiving services was the hoops that they had to jump through in order to access services. PP4 added that she felt that there was no consistency of information sharing between agencies and described her feeling that this shortcoming was a result of each agency starting from scratch. PP4 also described how, in order to provide consistency in P4's care, she has been keeping extensive records of the treatments P4 to ensure that all service providers are on the same page.

When asked if they felt that their children's service providers spoke to each other participants shared their different experiences of communication between service providers. PP4 was emphatic in saying that she did not feel that her family's service providers had communicated at all. She attributed this lack of communication to systemic constraints regarding confidentiality. PP4 cited the intervention of a particular service intervention (wraparound) in resolving many of the communication difficulties inherent in the system. PP1 shared a different experience where she experienced the community youth counselling agency reaching out to the children's hospital but that staff from the children's hospital appeared over-stretched and this made communication less than optimal. PP1 also said that she perceived significant attempts at connection between the youth counselling agency and the mental health hospital. PP4 chimed in to say that once service providers are given the opportunity to speak together with parents in a wraparound process the result was very helpful to PP4's family. PP3 shared how she felt the process of information sharing between the children's hospital and the youth community-counselling agency a straightforward process of signing consents. Both PP1 and PP4 spoke about the multiple assessments their children had experienced and their suspicions that these assessments may miss aspects of their children's experience. In the case of PP4 she shared her suspicions that P4 may have been under-reporting her experiences. PP4 and PP1 talked about how their children may be bored with the assessment process and that the assessments may therefore not reflect the complexity of their children and their struggles. Their observations were most closely connected to their children's entrances to different agencies. PP3 cited her experience of P3's assessments as quite straightforward due to his experience of a straightforward diagnosis from her perception. This was especially apparent when PP3 was asked about any confusion she may have experienced as a result of her interactions with different service providers. Her response was that both in the realm of psychiatric services (children's hospital) and family counselling (community youth counselling agency) her experience was

quite straightforward. PP3 attributed this straightforward experience to her training as a mental health professional and that her child had received a straightforward diagnosis. PP4 pointed out that because of P3's clear diagnosis it may have made PP3 and her child's journey through the mental health system more straightforward. In contrast, PP4 recounted experiencing the mental health system very confusing. She attributed this confusion to a divide between services meant to help youth with substance use and those services designed to help with mental health concerns. PP4 shared her personal experience of P4 as well as her experience of talking to other parents whose children who had similar experiences of what she described as self-medicating with illegal drugs. PP4 described her conviction that P4's underlying difficulties had to do with mental health issues which PP4 believed had contributed to P4's substance use problems. PP4 described how she had vigorously advocated for her daughter to receive concurrent counselling for mental health issues as well as substance use. For PP4 this was the most confusing part of her experience of collaborative care between substance use and mental health services. PP4 described how she experienced different messages from the people treating P4 for a substance use issue and the people providing treatment for P4's mental health needs. In particular, PP4 described the work she and her partner did to resolve the messages they received from their parent counsellor at the substance use agency and through their involvement with a dialectical behaviour therapy (DBT) treatment group at the children's hospital. PP1 described her similar experience with another of her children. In her case the substance use counselling agency had counselled PP1 and her family to focus on the issues associated with substance use. PP1 described her regret that her older child was unable to address their mental health issues concurrent to their substance use problems. PP1 spoke about her confidence that the mental health hospital was treating P1's mental health and substance use difficulties concurrently. She worried however that P1 was not being open about substance use. PP1 also spoke about how upon referral to the community youth counselling agency she had to be quite persistent and her family was assigned a number of counsellors. PP4 agreed with this feeling that "there were many false starts and we never really landed". Both PP1 and PP4 spoke about their experience of this community youth counselling agency evolving to offer more mental health services as their children was accessing the services of this agency.

When asked about their thoughts on gaps between services the participants mentioned lack of communication and difficulties accessing services. For example, in reference to the youth

community-counselling agency, PP3 spoke about the many attempts she needed to make to engage with counselling services. This was a gap as it was felt by PP3 that it took a lot of work to engage with this service. Participants also cited a lack of understanding from schools as a major gap in collaboration between services. In terms of mental health and addiction services PP4 and PP1 pointed to gaps between mental health and substance use services in that the substance use services appear to work from a completely different paradigm than those of the hospital based services. For example, PP4 described the hospital based services as saying “you can’t treat someone whose head is completely fogged from drugs”. Participants cited lack of available service providers, lack of early intervention and triage and proper systemic organization as major gaps. In essence, the current system cannot keep up with demand. All participants also cited that the expectation that family doctors would prescribe and monitor psychotropic medication as contributing to a major gap in services. These participants expressed their discomfort that a family doctor with a full practice has the time to monitor these medications. The participants all spoke about their sense of security in having a psychiatrist involved in their child’s care and their negative feelings about the trend towards family physicians monitoring these medications. Participants also did not have very pleasant things to say about school systems feeling that these systems often gave up on their children. As a contrast, PP1 spoke about her two children who both have different mental health difficulties and her feeling that the child who is the focus of this discussion was getting good support from their current school. All parents agreed that their child’s middle school experiences were most indicative of gaps in mental health services. When asked about what service providers did to ensure there were no gaps in services participants highlighted service providers making connections with other agencies and these service providers attending meetings with other service providers. In addition, agencies checking in with families about the progress of their children who had previously received services was appreciated even if these agencies were no longer involved. In addition, flexibility of workers to meet the young person where they were at was much appreciated. One of the large gaps cited by PP1 and PP4 was the lack of connection between acute and outpatient services (e.g., outpatient and emergency/ inpatient). All participants concluded by talking about their hopes for a more coherent system, better diagnostic tools, and better support for parents. All parents reiterated the massive amount of work it takes for parents to support a child with mental health difficulties.

## APPENDIX F: THEMES, CODES AND REPRESENTATIVE QUOTES FROM STAGE I INTERVIEWS

| Theme                             | Contributing Codes                                  | Representative Quotation                                                                                                                                                                                                                                                                                           |
|-----------------------------------|-----------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| MEANINGS OF PSYCHIATRIC DIAGNOSIS | <i>Thoughts about the organization of treatment</i> | Diane: <i>I think the inefficiency in the system is because of the lack of proper triage and assessment [of a mental health diagnosis] as early as possible when somebody is struggling."</i>                                                                                                                      |
|                                   | <i>Inconsistencies in diagnosis and treatment</i>   | Karen: <i>"You've got your depression diagnosis, but [mental health professionals] have no idea how to treat it. They don't know. You don't have the scan like we have for a cancer and everything. So it's all guesswork."</i>                                                                                    |
|                                   | <i>Diagnoses connected to medication</i>            | Dimitri: <i>I found that [referring to Children's Hospital staff] were always trying to get me on some sort of medication. That medication can always solve it. You know like they weren't trying to find different ways. It was just like, "oh this medication can help that, this medication can help that".</i> |

MEANINGS OF  
PSYCHOSOCIAL  
TREATMENT

*Agencies working in  
parallel*

Diane: *We have [Substance Use Counselling Agency] people to help us with drug problems. We have had [Community Agency] to help us with crisis intervention. We've had [Children's Hospital] at the table at various times to help us with the mental health issues.*

*Community Agency  
workers as people to  
talk to*

Olga: *So, [Children's Hospital] helped us. I really love everyone [in the ADHD clinic], it was really great and Dimitri really liked to go there and up until he was 17... And then we went for counselling to [Community Agency] just to you know, talk as well.*

*Community Agency  
workers organizing  
care*

Karen: *I think it was more [Community Agency] reaching out than the other way, [Children's Hospital] did try and reach out to and get a connection with [Community Agency], but I just get the sense that they're so busy at [Children's Hospital]. They will make the call but if you don't connect, they're on to the next thing. So, they don't have time. . . . I find and even now the [Community Agency worker] is reaching out to [Mental Health Hospital] and they're trying to organize wrap things so that everyone can figure out: what are you guys doing?*

|                                                |                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|------------------------------------------------|-------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| WORKING<br>WITHOUT A MAP                       | <i>Multiple points of contact</i>   | Diane: <i>“I think the problem is that there’s no consistency in sharing of information that, you know—one organization that knows about your kid isn’t being transferred over to another organization. So, you know, they’re starting from scratch, right?”</i>                                                                                                                                                                                                                                                                                                                                                   |
|                                                | <i>Missed phone calls</i>           | Olga: <i>“It was just uhh—the waiting period was painful like—I had to call and call [the Community Agency] and [it resulted in] miscommunication even from them to us, and then they had to re-start the process.”</i>                                                                                                                                                                                                                                                                                                                                                                                            |
| PARENTS<br>CONNECTING<br>THE PIECES OF<br>CARE | <i>Wishing for more information</i> | Diane: <i>When [Nicole] had her issue in grade 8, we were recommended to get an assessment done at [the Children’s Hospital], and we did get an assessment . . . and, at 14 [Nicole’s age then], we were not entitled to the report. . . [Diane wondered] “Why did that psychiatrist pat us on the head and say, ‘Oh, you should probably go get some counselling’? Why didn’t she send us to the [Children’s Hospital Outpatient] clinic? Immediately? . . . And two years later finally—two and half years later we finally get her into [Children’s Hospital clinic] where she should have been in grade 8.</i> |
|                                                | <i>Facilitating connections</i>     | Karen: <i>I got very angry at [Children’s Hospital] and you have to kind of stand your ground and tell them that you don’t think [Jonah] is ready to leave yet...we were at the [Children’s Hospital Emergency Department] many times before Jonah was let in [to inpatient treatment].</i>                                                                                                                                                                                                                                                                                                                        |
| EVIDENCE OF<br>COLLABORATION                   | <i>Physical presence</i>            | Joanne: <i>What [Behavioural Treatment Agency] did, which was fabulous, they started having [Community Agency Worker] come to the [case coordination]</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                          |

|                                        |                                                                                                                                                                                                                                                                                                                 |
|----------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                        | <i>meetings.</i>                                                                                                                                                                                                                                                                                                |
| <i>Getting people around the table</i> | Karen: So [Community Agency worker] <i>has been really trying to reach out to Jonah and really trying to with the people around the table</i> [referring to different service providers] <i>figure out who's doing what because she recognizes that Jonah has been bounced around.</i>                          |
| <i>Carrying the story forward</i>      | Jonah: <i>I find</i> [the Children's Hospital and the Mental Health Hospital] <i>are pretty good actually because I overdosed like two weeks ago and I had an appointment at</i> [Mental Health hospital] <i>with</i> [Mental Health Hospital psychiatrist] <i>and she already had the file and everything.</i> |
| <i>Consent forms</i>                   | Olga: <i>for</i> [the Community Agency] <i>talking to the psychiatrist from</i> [Children's Hospital] <i>I just needed a consent.</i>                                                                                                                                                                           |

**APPENDIX G: THEMES, CODES AND REPRESENTATIVE QUOTES FROM STAGE II INTERVIEWS**

## INITIAL INTERVIEWS

| Theme                  | Contributing Codes                                        | Representative Quotation                                                                                                                                                      |
|------------------------|-----------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| INITIAL<br>CONNECTIONS | <i>Feeling overwhelmed</i>                                | Dave: <i>It's either you struggle, struggle, struggle, and then you start getting help, and then all of a sudden, it's just like, all the doors open up.</i>                  |
|                        | <i>Tailored service offerings</i>                         | Nancy: <i>"They wanted to know what [the Community Agency counsellor] was doing with her and everything—building on [Elise's previous treatment]."</i>                        |
|                        | <i>Service providers facilitating information sharing</i> | Pakhi: <i>"We had a meeting before they told me that I could get out of the hospital. There was a community nurse there and there was someone from the Community Agency."</i> |

|                                              |                                                                                  |                                                                                                                                                                                                                                                                                                                                                                                                              |
|----------------------------------------------|----------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| ROLES IN<br>MAKING THE<br>TREATMENT<br>WORK. | <i>Evidence of<br/>collaboration</i>                                             | Pakhi: <i>“Well, I talked to all of them and I got the same response.”</i>                                                                                                                                                                                                                                                                                                                                   |
|                                              | <i>Consistency between<br/>service providers</i>                                 | Elise: <i>Because we had to sign a consent form from the [Children’s Hospital], to talk to my school and [ the Community Agency counsellor], and we had to talk to—we had to sign some before, I don’t remember—all I know is that we had to sign some consent forms.</i>                                                                                                                                    |
|                                              | <i>Communication<br/>breakdown</i>                                               | Catherine: <i>“It’s almost like going to [the Children’s Hospital Emergency Department] is a punishment then ’cause they waste so much time just going over everything again. It’s like, ‘Aren’t these written down somewhere?’”</i>                                                                                                                                                                         |
| PROFESSIONAL<br>CULTURES                     | <i>The Roles of the<br/>Children’s Hospital<br/>and the Community<br/>Agency</i> | For example, when I (Noah) asked Elise about her Community Agency counsellor Elise said, <i>“She is helping me with—What’s the word again? –my emotions, my feelings. And she’s helping us out with clothing, too, for me.”</i> I then asked Elise, <i>“What kind of stuff are you hoping [the Children’s Hospital will] help you out with?”</i> Elsie replied: <i>“To figure out what’s wrong with me.”</i> |

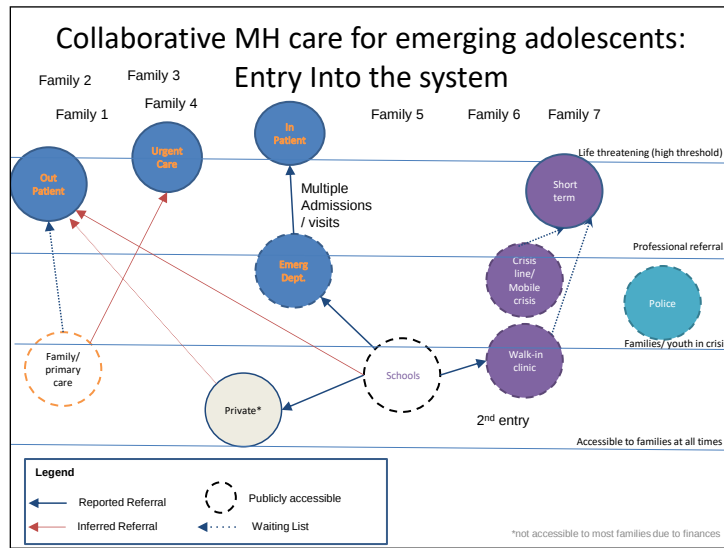
## THREE MONTH FOLLOW-UP INTERVIEWS

| Theme                 | Contributing Codes                 | Representative Quotation                                                                                                                                                                                                                                                                                                                                 |
|-----------------------|------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| FINDING<br>DIRECTION. | <i>Directionless</i>               | Dave: <i>“Not understanding fully what's going on, and then all of a sudden you have all these doctors trying to help you, but you don't know really what they're trying to get at, at times.”</i>                                                                                                                                                       |
|                       | <i>Lack of information sharing</i> | Elise: <i>Oh, or it's like my [Children's Hospital group counsellor] and my [community nurse]. We both come up with safety plans, why don't they just share them together? Yeah, like me and the [community nurse], we came up—we did a safety plan and everything; why didn't [the nurse] call [the Community Agency counsellor] and tell her that?</i> |

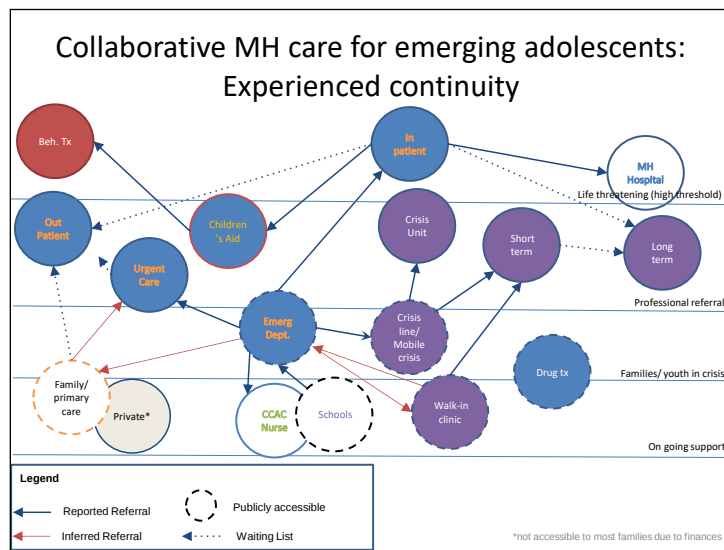
|                                                   |                                                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|---------------------------------------------------|----------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| MANAGING CARE.                                    | <i>Client transferring information</i>                                     | Catherine: <i>“The problem is, whenever we go to the Children's Hospital because of stuff, because they don't know [about Catherine's previous visits] they don't know anything. I have to sit there and repeat my whole story again, and then they're like, “Try this,” and I'm like, “I've tried that before. I've been here multiple times.”</i>                                                                                                                                                                                                                                  |
|                                                   | <i>Service providers sharing information</i>                               | Elise: <i>When I was admitted [to the Children's Hospital], they would talk. They would go—they'd call [the Community Agency counsellor], let her know what's happening, and all that stuff. And when I was in the hospital, like, when I was admitted, I know they had called [the Community Agency counsellor] to let her know how I was doing and everything, and they kept her updated and stuff.</i>                                                                                                                                                                            |
| YOUNG PEOPLE TAKING CONTROL OF THEIR INFORMATION. | <i>Youth making choices about who accesses their treatment information</i> | Pakhi: <i>It's like, there was a reason why I put on the consent form that there were certain people that I wasn't okay with communicating. Like for example, there used to be a [community nurse] that came to my school after I was discharged from the hospital, and she was allowed—I said that my parents were allowed to tell things to her, but she wasn't allowed to share certain things with, like, [the Children's Hospital] or my parents or with [the Community Agency], and she said to a certain extent that is okay unless it is concerning my safety and stuff.</i> |
| PROFESSIONAL CULTURES                             | <i>Who's in charge</i>                                                     | Catherine: <i>“It's kind of like, I don't know what it's called, with the two graphs, the big circles. . . . [the Children's Hospital] is one of them and then [the Community Agency] is the other, and then me and my pediatrician are in the middle.”</i>                                                                                                                                                                                                                                                                                                                          |

## APPENDIX H: INITIAL RESULTS PRESENTATION SLIDES

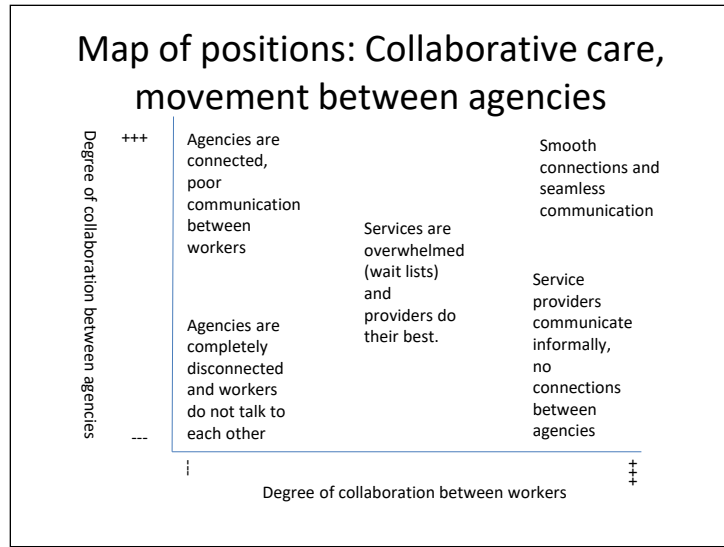
### Slide 1: Entry into the system



### Slide 2: Family experiences of continuity of care



### Slide 3: Maps of positions families shared on collaborative care between agencies



#### Slide 4: Questions to consider

### Questions to Consider

*Based on the themes and the map of the ways in which children and their families experience collaborative treatment for psychiatric diagnoses that was just presented to you:*

1. What stood out for you as a service provider?
2. What confirmed your understandings of the experience of collaborative care?
3. What were you surprised about?
4. Was there anything that you feel needs to be included that wasn't?
5. Is there anything in this presentation that could improve the experience of collaborative care?