Meaningful/Authentic Collaborative Practice in Child, Youth and Family Wellness in British Columbia: The Time is Now!

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Abstract

This thesis examines "Meaningful/Authentic Collaborative Practice in Child, Youth and Family Wellness, in British Columbia", exploring what meaningful collaboration is, why the ethics are critical to the practice, and how the process of collaboration, with individuals, as well as across systems, can transform the way we think about child and youth wellness, and how we design and deliver services for children and youth, leading to greater wellness for families as a whole.

"The real strength in human beings lies not in our ability to overpower others, but to connect with them: to listen to them and to be heard by them; to understand and be understood by them; to reach out to them and be reached out to."

~Jon Wilson

ACNOWLEDGEMENTS

I dedicate this work to the thousands of young people and their families that I have been honored, and privileged to work with over the previous eight years. Their courage, determination, and strength, often despite immense stigma and a deep sense of nonfinite grief and loss, inspires me, immensely, each and every day.

It is also with immense appreciation to the talented, wise and empathic professors at City University, Vancouver Campus, especially Dr. Colin Saunders and Chris Kinman, M.C., that I find myself viewing the world through a lens, with metaphors such as "rhizomes", which will carry me forward, with a profound sense of collaborative ethics. Jacqueline Walters, your knowledge of the theory, as well as the ethics embedded within collaborative practice deeply resonated with me, and guided me to choose this topic. All of your support and has been duly noted, and most sincerely appreciated.

Last, but certainly not least, I would like to dedicate this work to my four intelligent, caring, insightful, and determined young adult "children", Ryan, Brett, Taylor and Marlie, for you all have truly been my greatest teachers, and it is through you that I have found my passion in life. Thank you for teaching me about patience, acceptance, compassion, and an "authentic" understanding of the urgent need for collaborative practice. Further, I wish to extend my deepest love and acknowledgement to my friends and family, for continuing to encourage and believe in me, every step along my journey.

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Chapter One

Introduction

My thesis is titled "Meaningful/Authentic Collaborative Practice in Child, Youth and Family Wellness, in British Columbia: The Time is Now!" This topic is important as "the core concerns with child and youth mental health [services and its] system include fragmentation and siloed services" (Chou et al., 2015). More importantly, "there is sufficient evidence that demonstrates the necessity to engage with families in child and youth mental health as families, children and youth are intrinsically woven together, as are their mental health needs" (Chovil, 2009).

Further, collaborative practice in child and youth wellness services is crucial as families and youth report feelings of significant stigma around mental health and substance use challenges which leads to major barriers to service access for children and youth. When systems and services are difficult to access, and families and youth additionally feel stigmatized and "shamed and blamed", they are less likely to seek out supports and treatment for their children and youth. In fact, less than 20% of youth with mental health concerns actually access services for treatment" (B.C. Select Standing Committee, *Interim Report* (BCSSC), 2014).

Further, in 2013, the McCreary Centre Society Adolescent Health Survey (MCSAHS) "showed that youth [and their families] do not access services for a range of reasons, including fear of stigmatization or denial of a condition". Additionally, and to compound all of the

above, British Columbia has the highest rate of child poverty in Canada, at 20.4% (*Just the Facts,* 2016). Poverty is a significant risk factor for children and youth, for developing mental wellness challenges, and as research shows "youth who went to bed hungry talked about how it affected their mental and physical health" (Adolescent Health Survey, 2013, p. 42).

The challenge of mental wellness concerns for children, youth and their families is not going to simply disappear and go away. "Diagnosable psychiatric disorders affect about 15% of Canadian children and youth" (Waddell & Shepperd, 2002). This amounts to 2 million children or youth, or 4-5 students in every classroom of thirty students across the country" (Davidson et al., 2010). Not to mention, as many as "75% of children and youth with a mental health problem or illness will not receive treatment" (Right By You, 2016). All of the above statistics clearly highlight not only a serious issue with child and youth wellness in Canada, and particularly here in British Columbia, the statistics also demonstrate how seriously flawed the mental health care system is, where a large majority of children and youth are without access, or not seeking help and support. The question begs asking, why?

This thesis will highlight why the above may be happening and how meaningful collaborative practice, including "collaboration with families in the care [of their young person, as well as collaboration with regards to mental wellness service design and delivery] …., according to Peraeault et al., (2011), not only contributes to [family and youth's] satisfaction with the services but also helps ease [families] burden" (Lavoie et al., 2012). Therefore, this thesis hopes to demonstrate that through more effective and holistic, meaningful collaborative practice approaches; developed *with* families, the result can lead to improved child and youth and family mental wellness.

"Together, young people, parents and professionals share a sense of urgency to

transform the child and youth mental health system. Being heard is a starting point, but being heard is not enough. Young people, parents and families want to see practices, policies, programs and services that reflect their values" (Evergreen Framework, 2008). By shifting to an authentic and meaningful collaborative working relationship, with families and systems; service access, service design and delivery can be enhanced, and embedded within this collaborative process, I also believe that a reduction in the stigma of child, youth and family mental health will follow.

Definitions

Collaborative Practice

Collaborative practice is not an easy task. Defining collaborative practice is equally challenging, as the literature reveals. In fact, it is so complex that the literature highlights how there is no clear definition of collaborative practice. Collaborative practice could be described as, "in its simplest form, …as primarily representing a broad challenge to a cultural shift away from fixed metanarratives, privileged discourses, and universal truths…and is characterized by uncertainty, unpredictability, and the unknown" (Meuller-Vollmer, 1989) (Anderson, 2013, p. 14). Similarly, constructionists believe that "meaning must be seen…as the co-production of speaker and listener, where both share in the same active power of linguistic competence".

Reynold's (2010) definition states collaborative practice is a "relational, dialogical "conversation" with the goal of supporting people or systems, in whatever goal or life's circumstance they wish to discuss,… embracing a value system consistent with post-modern, constructionist thinking, and is at the very core of one's "way of being." In my opinion,

Reynolds definition refers to a philosophy whereby an expert to expert dialogue evolves between individuals, families or systems, valuing diverse and potentially opposing viewpoints, within the framework of a shared goal.

Definitions from Australian researchers state that collaborative practice is about "producing something new, from the interactions of people and organizations, their knowledge and resources" (Acri et al., 2009). Researchers Kates et al., (2011), refer to collaborative practice as "care that is delivered by providers from different specialties, disciplines, or sectors working together to offer complementary services and mutual support". Further, and most important to the above definitions is that "collaborative [practice] also extends to the meaningful involvement of families, youth and individuals with lived experience in mental health services" (McDonald, Rosier, 2011). According to Chou et al., (2015), five core principles emerge, when trying to define collaborative practice. These core principles are sharing, partnership, interdependency, power and process. [Speaking to all of the above], there are many dimensions to collaboration". Indeed, there is no-clear-cut definition of meaningful collaborative practice, however the essence of all of the above definitions frames my working definition for this paper.

Mental Health

"The Mental Health Commission of Canada provides a useful definition of mental health:

> *Mental health* is different from the absence of mental illness, and is integral to our overall health. Mental health is a state of well-being in which the individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his own community (Mental health Commission Of Canada (MHCC), 2012, p.7).
>
> *Mental health problems and illnesses* are patterns of behavior, thinking or emotions that bring some level of distress, suffering or impairment in areas

> such as school, work, social and family interactions or the ability to live independently. They range from more common mental health problems and illnesses such as anxiety and depression to less common ones such as schizophrenia and bipolar disorder (MHCC, 2012, p.7).

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Important Clarification and Mental Health Challenges

Throughout this thesis I will refer to mental health, mental wellness, mental health problems and mental illness, interchangeably, despite there being obvious differences and distinct definitions. Mental health and illness rests along a continuum, a spectrum and one can have a diagnosis of mental illness and be mentally healthy, and likewise one does not require a mental illness diagnosis to be, or become mentally unwell. It is also paramount to my philosophy within this thesis that:

> There is no single cause of any mental health problem or illness, and no one is immune, no matter where they live, how old or young they are or their social standing. Mental health problems and illnesses are thought to be the result of a complex mix of social, economic, psychological, biological, and genetic factors that also influence our overall mental health and well-being (MHCC, 2012).

All of the above sets the stage for a comprehensive, thorough examination of collaborative practice, both individually, as a service provider, across disciplines, from therapist, to social worker to psychiatrist to educator; to system-wide, inter-agency collaboration, with the goal of examining the what, the how and certainly the why of authentic practice, in seeking to increase access to services and supports by families, reducing stigma of

mental health and reducing the traumatic effects, such as nonfinite loss and grief on families, due to young people's mental health challenges.

The Importance of Collaborative Practice

Collaborative practice is not only important to child, youth and family wellness, both from a family perspective, as well as from a system change perspective; it is, in my opinion, critical. Collaborative practice research suggests that "research established in partnership with …youth and families rather than solely driven by researchers may provide a more immediate opportunity to make a real and significant difference to the lives of those with lived experience" (Davidson et al., 2010).

My hope is to provide key recommendations, based on the literature, about how "meaningful" collaborative practice may guide families, therapists, researchers and systems at large, towards informed and improved supports, service design, delivery and certainly evaluation, of all of the above. As the following quote highlights, one form of collaborative practice that may offer a "new" way of co-creating meaningful collaboration is exploring "changes to the current relationship between researchers and … youth and parents [that] may offer an opportunity to advance the research agenda in a manner that may meet multiple needs simultaneously" (Davidson et al., 2010). It is my belief that meaningful and effective collaborative research and evaluation may lead to improved outcomes in mental wellness for children, youth and their families and have the potential to transform mental health systems for child and youth mental wellness.

This thesis will examine the research on collaborative practice, its history and its place as a model for shifting supports, services and systems within child and youth and family wellness, in the future. One critical element to achieving meaningful, authentic collaborative

practice is evidenced in this quote from the National Federation of Families (2008), regarding the paradigm shift of how parents and families are often viewed by professionals. “The paradigm shift of viewing parents as the source of the problems to active partners in treatment [and system change] has taken over two decades.”

Key Research Questions:

In my examination of the literature I will look for answers to the following questions: What is collaborative practice? What are the key elements of collaborative practice? What values, beliefs and ethics are necessary to be authentically collaborative? What barriers are there to collaborative practice and how do we overcome these? How can we work collaboratively across disciplines, from an individual, as well as systems lens, within child and youth mental wellness, looking at some examples of best practices, to promote better outcomes for children, youth and their families? How might collaborative practice benefit families, in terms of potentially reducing non-finite loss and grief as well as stigma of mental health? Further, what does non-finite loss and grief have to do with collaborative practice? Further, I will look at the above from an individual as well as system wide perspective, highlighting how the process of collaborative practice can greatly improve families functioning as a whole.

Organization of Thesis

My thesis will be a compilation of five chapters on different aspects of collaborative practice. First, I will speak to the what of collaborative practice, detailing the ongoing and evolving definitions of collaborative practice and examining the history of this theoretical approach. I will outline in great detail, examples of authentic collaborative practice and

examine how individuals and systems as a whole might examine their practices, seeking to better support child and youth wellness challenges.

In Chapter Two, I will examine the why of collaborative practice, examining the ethics and values behind the practice, utilizing current literature, which examines the how and the why.

Chapter Three will discuss the positive influence that collaborative practice may have on families, when coping with their young person's mental wellness, and how the trauma of non-finite loss and grief, which is largely unrecognized, often plays a key role in how families manage. I will explore non-finite loss and grief and how this additional challenge impacts the mental health and well-being of families as a whole. In examining the family experience of non-finite loss and grief, I will highlight how collaborative practice can increase access, supports, and improve service delivery and design. Further, I seek to explore the question of how meaningful collaborative practice may result in a reduction in child, youth and family stigma in mental health, which is critical to family wellness.

In my fourth and final chapter before concluding, I wish to highlight the research behind family support groups and the best practices of self- help groups to elicit more effective, meaningful collaboration between families and professionals, exploring collaborative practice from an individual as well as system reform lens. Moreover, throughout Chapter Four, I will highlight recent best practice examples in particular in Canada, and British Columbia. I will feature the F.O.R.C.E. Society for Kid's Mental Health, established and co-founded in 2000, by two mothers, which has been instrumental in collaboratively shifting practice and policy in B.C. Numerous additional best-practice

collaborative examples will be highlighted, where family and professional-led support groups may help demonstrate the how of authentic collaboration.

Literature Review

Collaborative practice has many off shoots and similar yet slightly different terms, practices and research initiatives, some of which include Person Centered, Family Centered, Co- Production, Family Engagement, Family Involvement, Patient and Family Centered Care, Trauma Informed Practice, as well as Collaborative Research and Evaluation and Participatory Action Research. To date, my review is based on literature from over seventy peer-reviewed scientific journals, books, technical reports, policy papers, planning documents from Canadian and international child and youth mental health agencies as well as searches from inter-disciplines, such as child welfare, education, and juvenile justice.

I have looked at the major works such as *The Evergreen Framework* (2012), *Healthy Minds, Healthy People, A Ten Year Plan to Address Mental Health and Substance Use in British Columbia* (2010), The National Institute of Families & The F.O.R.C.E. Society, *BC FamilySmart Network Framework* (2014), *The Ministry of Health Services and the Ministry of Children and Family Development Select Standing Committee Interim Report on Youth Mental Health* (2014), *The Final Report from the BC Select Standing Committee, Concrete Actions for Systemic Change (2016), Healthy Minds, Healthy People Engagement Summary* (2014), *The Canadian Collaborative Mental Health Charter* (2006), *The Mental Health Commission of Canada, National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses* (2013), *Trauma Informed Practice Guide* (2013), *Community Action Initiative, Collaboration to Address*

Mental Health and Substance Use; Successful Stakeholder Engagement, Focus on Mental Health and Substance use Clients (2014), The Representative for Children and Youth, *Still Waiting Report* (2013), The McCreary Centre Society *Adolescent Health Survey* (2013), and the *Changing Directions, Changing Lives, Mental Health Strategy,* (2012), just to name a few.

Through the research, I have identified some major themes in serious systemic flaws, demonstrating the urgent need for meaningful collaborative practice, which include:

> Fragmented and siloed services, difficulty navigating the mental health system, lack of understanding of mental health problems, lack of support for parents and caregivers, lack of youth friendly services, lack of parent and caregiver involvement, lack of information sharing across disciples, from the emergency department to primary care physicians to school settings, and lack of transition planning for youth moving to adult mental health services (*Still Waiting,* 2013).

These system "flaws" and gaps briefly describe some of the key findings of my literature review that relate directly to the urgent need for collaborative practice, not only system wide, but also with individual service providers, as I will highlight below, the research shows collaborative practice has merit and applicability in child and youth and family wellness (*Still Waiting*, 2013).

Another key finding relating to the need for collaboration within child and youth wellness care is not simply the what of collaboration, but most importantly the *'how"*; including, "sharing, partnership, interdependency, power and the process" (*Families Matter Framework for Family Mental Health in British Columbia,* 2012). The *Framework* is one of several recent documents, which are crucial for B.C., in that they are "intended as a guide towards developing and implementing policies and practices …which is [needed] to increase collaboration with families and youth (Anderson & Lees, 2012).

Another important point raised in the above *Family Matters Framework*, is the strong emphasis for the need to reduce stigma of child and youth mental health.

> The pervasive and debilitating nature of stigma and discrimination continues… despite advances in [families knowledge]… [whereby it is internalized by the person and the family with a mental health challenge, by the professionals and service systems designated to help them, and promulgated by the media and popular culture
> (Families Matter Framework, 2012).

This point is critical to my thesis, in relation to collaborative practice, when done in a meaningful way, results in reduced stigma and increased access to youth and family "focused" supports and services. (At least that is the strong premise of this thesis, and a point I will hope to demonstrate through research, and evidence-based approaches, as well as evidence-informed "best practices").

Not only are the above key themes emerging as compelling reasons for increasing efforts towards meaningful collaborative practice with children, youth and families, as well as across mental health care systems, further research is needed to identify the how. In other words, "collaborative partnerships between families and the people, organizations and systems that influence daily life are critical in overcoming stigma and discrimination and supporting family resilience" (Anderson & Lees, 2012).

History of Collaborative Practice

The history of collaborative practice has its roots in the Family Movement of the 1980's, where "caretakers were blamed for frequently using unclear communication styles that [according to professionals at that time], caused a disruption in attention (Kymalainen & Weisman de Mamani, 2008)". Even more, as recently as 2001, a sociology text states "there is

solid scientific evidence for what our grandparents always believed; parents are to blame when their children misbehave (Stark, 2001). With the above scientific evidence and professional stance behind this evidence, it is of no surprise that families not only require but need change, in order to be better equipped and more helpful to their children and youth, and begin to demand that they (families) be "considered part of the solution rather than identified as the source" (Federation of Families, 2008).

Notwithstanding the above stigma and discrimination towards families with children and youth with mental health challenges, a shift towards more family-centered approaches, such as Minuchin (1998) who took the practice of family-centered, collaborative therapy, to a new level.

Collaborative practice and the ethics behind the theory, is important to me for many reasons. It is the foundation of the work I have done for over seven years, with the F.O.R.C.E. Society for Kid's Mental Health in British Columbia. The F.O.R.C.E. Society merged as of July 2015, with the National FamilySmart Institute of Families, which was co-founded in 2011 by Keli Anderson and Dr. Jana Davidson.

In 2000, The F.O.RC.E. Society was co-founded in British Columbia, by two mothers whose young people were significantly affected my mental health challenges. One of the co-founders had lost her son to suicide, and the other mother, Keli Anderson, has a son who was diagnosed with bipolar disorder at age ten. Both families felt alone, unsure of where to get help, and feeling intense stigma from professionals as well as educators.

Over the previous sixteen years, the collaborative work of the F.O.R.C.E. in British Columbia continues to grow. The birth of this organization was, and continues to be inspired by the work of Sandra Spencer who founded the National Federation of Families (1989) in the

United States. “Family organizations like the National Federation of Families for Children’s Mental Health… has been a powerful movement in directing the … transformation [of mental health systems] and…moving towards a ‘system of care’ which includes family involvement, [and collaboration]” (Tannen, 1996).

As with the above recent collaborative practice exemplars, the basis for collaborative practice began with Carl Rogers (1951). Rogers identified the elements of the therapeutic relationship being at the core (of therapy). Just as Rogers’ core components of the therapeutic alliance require the factors of trust, respect, empathy and “genuiness” or meaningful connection, as I suggest, “the importance of engaging families [by listening, respecting, being empathic and genuine], is being increasingly recognized as best practice in providing quality services in child and youth mental health” (Chovil, 2009). Further, Rogers’ therapeutic alliance merged into Family Systems Therapy, where the Milan Group’s work with the Reflecting Teams, also influenced and enhanced collaborative practice. Further, Minuchin (1998) was also instrumental in looking at borrowing from practices, and ultimately viewing families as inherently strong and being partners in the process.

Research Strategies

In commencing my research into collaborative practice I needed to use many search terms, including therapeutic alliance. I searched the library catalogues, both at City University and University of British Columbia, via online and in person. I examined historical as well as the most recent research under many related headings such as; person-centered, family-driven, family- centered care, FamilySmart, reflecting team, shared care, inter-professional collaboration, collaborative practice, shared decision-making, peer-led, lived experience,

participatory action research, collaborative care, partnership, family engagement, interdependency, collaborative process, family caregivers, family support, mental health care, engagement models, trauma informed practice, stigma, service barriers, grief and loss, integrated care, family participation, family support organizations, system change, policy, system of care evaluations, health care reform, collaborative research and evaluation, co-production, professional collaboration, mutual support, discrimination, and inequality, to name a few!

I also searched key names, such as Carl Rogers (1951), the Milan Team (1978), Tom Andersen's Reflecting Team (1987), and the work of Michael White and David Epston (1990), among others, as evidenced in my reference pages.

The above searches generated thousands of articles and books. Clearly this was far too many and far too broad of a search. I skimmed the lists of titles generated and discovered that a variety of key words emerged which supported me in generating the more narrowed focus around collaborative practice, the ethics and values of collaborative practice, child and youth mental health and wellness, and system reform. I needed to set limits on the above child wellness and system change collaboration concepts by keeping the key phrase of Collaborative Practice in Child, Youth and Family Wellness at the forefront of my mind. I utilized the strategy of a "literature map" (Cresswell, 2014), to divide the topic into key concepts. I utilized abstracts and summaries to glean the relevant information required to narrow my search. I focused in on the critiques of the articles as well, looking at potential research flaws (Cresswell, 2014, Cooper, 2010). Additionally, I examined quantitative as well as qualitative or "mixed methods" approaches.

Within my thesis, I plan to weave the specific topic of collaboration with families, professionals and systems, throughout, as well as highlight the significant benefits of collaborative practice, with respect to how families and youth, dealing with significant challenges *feel*. Having said that, I needed to set limits around collaborative practice, such as adult mental health, or specific substance use collaborative practice, or even details regarding the specifics of family engagement strategies, participatory action research or collaborative evaluation research. All of the above are examples of topics that had to be eliminated from my thesis proposal, and ultimately my thesis about collaborative practice.

Method

The method of inquiry I will use for my thesis is from a manuscript style, yet a "transformative paradigm theory" (Cresswell, 2014) would be recommended for much needed future research into meaningful collaborative practice in child, youth and family wellness. "The literature is growing on the use of the transformative framework and mixed methods research… and it is particularly applicable to the study of community health issues and the study of marginalized groups…(Cresswell, 2014), of which families with young people with mental wellness challenges, are very much "marginalized", as will be evidenced throughout this thesis.

Indeed, I assert that children, youth and their families have been marginalized through the stigma and discrimination they face regarding mental health challenges and illnesses. Transformative theory and framework takes a "broad philosophical worldview….[that positions itself by using] a lens for looking at a problem recognizing power and social relationships… [and] to improve people, [systems] and society" (Cresswell, 2014). In other

words, a key piece of transformative theory and research is about "involving the community of interest in the process, speaking about family experiences …and how my work experiences and background, have shaped [my] understanding of [families]" (Cresswell, 2014)… and additionally, how my experiences have and continue to shape my ethical and "collaborative stance".

Results

My thesis will highlight current and future outcomes of collaborative practice, as globally defined above. I will incorporate examples of research, such as the " meta- analysis, comprised of 37 randomized studies of nearly 12, 500 participants, collaborative care strategies were among the more effective than the standard of care for depression and anxiety in both short and long- term measures (FamilySmart, 2014). Similarly, I will utilize research that illustrates that a key reason that only 1 out of 4 children and/or youth access services is due to stigma, the stigma of mental health challenges, and the stigma from "systems" and society at large.

I will identify how engaging in meaningful collaborative practice (both from an individual, as well as from a systems level) families and children and youth feel more empowered and seek out treatment, both earlier and more often. In fact, recent studies highlight this major challenge, as "75% of children and youth with a mental health problem or illness will not receive treatment" (Waddell, Shepherd, 20020).

Moreover, "drop out" rates for youth in therapy, is also high. This is a huge issue and one that collaborative practice, where stigma is reduced, may increase youth and family engagement. Through increased engagement, by way of meaningful collaborative practice,

both individually and systemically, my hope would be that the trauma of nonfinite loss and grief might be reduced, leading to greater family coping and wellness, as a whole.

For example, outcomes studies show that when engaging in meaningful collaborative practice, where people feel validated, respected, listened to and heard, they may not only increase their use of services and supports, they may continue longer with the services. This is important as 20% of young people in Canada have a diagnosable mental illness (Right by You, 2016) and even more alarming is that by 2030, it is predicted that depression will be the leading cause of disability in high- income countries.

Throughout this thesis I will highlight key aspects of the limited research that clearly points to the urgent need to conduct future research with children, youth and families from a collaborative model; shaping, informing, designing and producing more effective systems of care for children, youth and their families.

Research shows that mental health is a critical issue and the need for improved outcomes is highlighted above. Collaborative practice has shown to not only enhance "the expertise that families have, with respect to their needs and experiences with child youth mental [health] care, [families expertise] is invaluable to training [and working] with professionals" (Chovil, 2009). Family expertise can then be formally shared across systems, collaboratively, such as in the current best practice example of the Provincial Child and Youth Mental Health and Substance use Collaborative, which *is* informing future policies and practices.

Discussion

Chapter One

As briefly mentioned above, my thesis will be divided into five chapters. Collaborative practice examples will be woven throughout the chapters, examining first Collaborative Practice, looking closely at what it is…and what it is not. I will examine what collaborative practice means, detailing the history of this practice. I will discuss evolving ideas around collaborative and collective ethics and the concepts, philosophies, qualities and values that inform and frame the ethical practice. Further, I will look at specific influences and inspirations that contribute to how we collectively remain accountable, compassionate, aware, and also able to attend to social justice issues.

Throughout the thesis I will elaborate on ongoing efforts to track ethical positioning, both with individuals as well as within systems. I will outline self- care and reflective practice strategies that help ensure we, as clinicians, are practicing in a respectful, beneficial and meaningful ethical and socially just manner. I will utilize recent peer reviewed articles from leading therapists and social justice activists to emphasize the unique sense of collaborative ethics, which is, at the very root, collaborative, person centered and highly inter-disciplinary.

Chapter Two

In Chapter Two, I will examine the why of Collaborative Practice, examining the ethics and values inherent in the practice. "Collaborative practice offers hope, possibilities, options, and personal empowerment by bringing to light inner resources, strengths and pre-existing competencies that perhaps the person(s) [and systems] were unaware of or had simply forgotten about" (Federation of Families, 2008). Not only does the collaborative practice model focus on strengths and resiliencies, this model is relational in all aspects, which is proven to enhance therapeutic [and other desired collaborative] outcome[s]. In fact, as

researcher Lampbert (1992) indicates, “therapeutic relationship accounts for 30% of a person(s) outcome, regardless of technique” (Miller & Duncan, 1997).

It is my belief that, similar to the above research, meaningful collaborative practice may account for a large percent of the required outcome, systemically speaking. In addition, to the aforementioned, collaborative practice helps create a new, multiple-perspective lens, leading to increased hope for present and future possibilities. It “co-create{s] relationships of *enough safety*,… [from] a stance that drives, sustains and invites continuing development,…[utilizing] ever transforming questions..”(Reynolds, 2010). Inviting hope and optimism leads to another key factor in collaborative goals and outcome, “the placebo effect”. Hope, or the placebo effect is proven to account for up to 15% of desired… outcome. Similarly, collaborative practice “create[s] a space for, invite[s] and foster[s] conversations and relationships [to] connect, collaborate and construct with each other” (Sheldon, et al., 2007).

To re-iterate, the above-mentioned challenges and complexity of collaborative practice, as evidenced alone, by its lack of a clear-cut definition, further literature shows that “the compilation of evidence about family and youth…[collaboration] has been complicated by a lack of shared assumptions about the value of [collaboration]. Family members and youth, along with like-minded professionals, often assume that the value of increasing family participation and influence is self-evident and inherently desirable” (Friesen, et al., 2011).

The ethics of collaborative practice pertains to our own “ethics, which are not fixed and static, but fluid and living. We breathe life into our ethical engagement by continually being open to new learning and new possibilities…” (Reynolds, 2010, p. 24). These values, as Reynolds describes above, speak to the values and shared assumptions, required for

meaningful collaborative practice. The above issue of shared assumptions, stigma, "moral authority" of professionals, as well as many other challenges of collaboration, make this topic an important and an urgently needed one.

Chapter Three

Tying in with all of the above, I will examine non-finite loss and grief and the stigma so often associated with the raising of a young person with mental wellness challenges. Given the chronic and traumatic experiences that surface, as a result of these challenges many families face this additional burden, which until recently goes largely unrecognized. I will outline what non-finite loss and grief is, and examine the numerous ways that stigma adds to the severe burden a parent/caregiver faces, and how all of the above adds to the trauma, which significantly negatively impact family's lives.

As Bruce & Schultz (2002) state, "nonfinite losses are those loss experiences that are enduring in nature, usually precipitated by a negative life event or episode that retains a physical and/or psychological presence in an ongoing manner' (Winokuer, Harris, 2012). I will examine how the trauma of non-finite loss and grief may be reduced when one is offered a collaborative, non-judgmental approach to working together towards shared goals.

My question is, "How can families be empowered, and have an open dialogue and be an equal and meaningful collaborative partner, for example within an integrated team at Child and Youth Mental Health, if there is an underlying elephant in the room, implied or stated, that the family may be the *cause* for a child or youth's dysfunction? The language of a biological/ medical model and mental health diagnoses *is* stigmatizing. The language of counseling, a psychosocial model can *also* be stigmatizing. The above *is* pathologizing and the oft-asked

question, “What happened?” implies something went awry. Again, how can we ever hope to support and empower a child or youth, if at the same time we disempower the parents and caregivers? This piece of the puzzle is one I ponder, fight for, and speak about, throughout this thesis. I ask you to ponder these same questions.

Chapter Four

The fourth chapter in this thesis will look at collaborative practice from the perspective of a peer and/or professional-led family support group lens. The chapter is titled, “Peer-Led versus Professional-led Support Groups for Family Members with Children or Youth with a Mental Health or Wellness Challenges: Collaboration Is Best!” I will highlight the different therapeutic factors that emerge in both peer and professional-led family support groups and look at the research and lack thereof around what factors lead to effective collaboration between and amongst professionals and families with regards to family support groups, for families with children or youth with mental health challenges. I will pose questions about the effectiveness of both groups and examine the research around best practices for peer/professional collaboration in support group settings.

Conclusion

My fifth and final chapter will provide an overview of all of the above, summarizing the key points about collaborative practice, again utilizing the literature, as described above. Additionally, I will highlight how complex and challenging meaningful collaborative practice can be, and yet most assuredly, it is “increasing in interest and support in British Columbia” (Chovil, 2009). It is clear that collaborative practice is not new, yet collaborative research and evaluation and collaborative practice within systems, is a relatively new approach or model,

which as yet, has little research in child and youth wellness. "Despite the established benefits of family-centered [collaborative] care and its precedence in other fields, it is relatively unfamiliar to children's mental health" (Chou et al., 2014). I will highlight how this is changing!

What is of key importance is that collaborative practice can be used to " [meld] family systems, concepts and practices within complex larger systems, including medical (Doherty, McDaniel, & Hepworth, 2014), family court (Emery, 2014), foster care (Lewis, 2011), child protective services and mental health agencies (Madsen, 2014, Madsen & Gillespie, 2014), prisons (Baker, McHale, Strozier, & Cecil, 2010) and immigration (Falicov, 2014), (Imber-Black, 2014). Its cross-sectorial and cross-"issue" application is truly a philosophy that can shift systems.

Lastly, despite advances in the involvement of families as meaningful participants in the field of children's mental health, more work is needed to become true partners in treatment, planning, service or system development, and paid providers of care" (National Federation of Families, 2012). Further, as the *Evergreen Framework* (2010) states, "If these values inform the transformation of the child and youth mental health system, we feel certain that young people and families will engage to assist in the creation of positive change…" It is my hope to explore collaborative practice and its many dimensions, which, if meaningfully applied, has great potential to inform the future of child and youth and family mental wellness in British Columbia.

Chapter Two

Collaborative Practice, It's All About Values

Introduction

This chapter further discusses the what of collaborative practice, exploring the history, the "theory" and most importantly, the how and why around the ethics and accountability of collaborative practice, involving the philosophy behind it. Peer reviewed articles from leading therapists and social justice activists are utilized to emphasize the inter-disciplinary perspective that collaborative practice embodies.

What is Collaborative Practice?

Collaborative practice is many things. In contrast, it is most notably *not* certain things. In fact, many might argue that it is not a practice at all, in the traditional sense of therapist as the expert. It is more in keeping with and best described as a practice. For the sake of this paper, it will be referred to as practice, with the term therapist to describe one member of the practice. The other member will be referred to as a person[s) versus a client, which creates a image that seems against the collaborative practice model.

Collaborative practice is a relational based philosophy of life, embracing values over technique. It is "a philosophical stance, a "way of being" in relationship and conversation." (Anderson, 1997,p.43). It is not directive, nor does it use a technique to teach skills. It truly is a way of being which transcends practice. "It challenges institutional traditions such as

boundaries and self-disclosure as critical to proper and successful practice." (Anderson,1997, p. 53).

To be able to offer effective collaborative practice, on an individual level, it requires the therapist to fully embrace and/ or live by the values congruent with the theory, whereby a therapist authentically engages inter-relationally, versus intra-psychically, to "walk alongside" the person(s), in an "as if" stance of exploring possibilities and new ways of viewing a situation. There is no notion of right or wrong. It is not focused on the problem. It is mainly present and future oriented, inviting a dialogical conversation, discovering and uncovering inner resources, through mutual dialogue. As Jeff Chang (2013) writes, it is a "collaborative conversation, rather than a top-down, expert-to-client endeavour".

In collaborative practice, again, in the case of individual therapy, with a therapist and a client/clients, there is no hierarchal structure of therapist knowing best. In fact, quite the opposite, whereby the therapist embraces an authentic "not knowing" stance, where the person(s) and the therapist co-create what is discussed, how it is discussed and what, if anything the person(s) might do, about any possible next steps. Individual therapy as well as how the model or practice applies to system wide collaboration, is no different.

I will be discussing both individual and system collaboration throughout this thesis, and providing research and best- practice examples. This chapter speaks mainly from the reference point of individual therapists with clients, however I want to emphasize that the key elements of collaborative practice, which I have spoken to in Chapter One and will outline in more detail in this chapter, are also critical to keep in mind as I speak in subsequent chapter to the need for and challenges around systemic collaborations.

Further to the above, looking at the how and the why of collaborative practice, a basic premise is, we, collectively must learn and accept uncertainty. The "not knowing" and curious stance is a philosophy as well as a "way of being". "The therapist [or organization], invites the person(s) into a mutual or shared inquiry about the issues at hand." (Anderson, 1997, p.47). The point should be made that this is not to suggest that participants in the collaborative "process" are passive. As Minuchin (2011) believes, "there is a basic concept about the process of …… change and about the [participants or] therapists responsibility for shaping that process".

Further to the above, a description of collaborative practice requires the use of adjectives as opposed to formulas and technique. It speaks to values and the critical importance of a therapists' congruency with the model and its values, leading to a respectful "shared inquiry", between two or more people. This therapist, and the group she is working with, will invite a present and/or future orientation; they will be focused and centred, as well as strengths based. Curiosity, unconditional positive regard and openness are key attributes, where a "not knowing" attitude is central to the conversation.

Values, philosophy of life and an ethical stance are all descriptors of what collaborative practice encompasses, in order to "walk the walk" and authentically engage inter-relationally, with and alongside a person(s). As evidenced above, collaborative practice is about a stance, a philosophy, a way of being and conversely, it is explicit that it is not about a technique. "We have become over fascinated with techniques…but what you are in the relationship is much more important" (Heppner, Rogers, et al.,1984).

Similarly, as Vikki Reynolds (2010) asserts, "I am engaging with an understanding of ethics that is less connected with philosophical and hypothetical judgments of right and

wrong, and more attuned to the immediate demands of circumstances in the social context of the lives of person(s).” This speaks to the present and future focused relational therapeutic conversation that takes place within collaborative practice, with the intent on the part of therapists to be helpful and invite hope and healing. Through the mutual exploration of new possibilities and co-creating an alternative, multi-perspective lens, collaborative practice enhances and brings into awareness the person’s library of competence.

Who and When: A Brief History

Collaborative practice is part of the post-modern movement away from “hierarchal strategy to collaborative inquiry” (Anderson, Gehart, p.24). As Bateson (1988) states, “human languages- especially those of the West- are peculiar in giving undue emphasis to Separable Things. The relationship is not upon “relations between” but upon the ends of relationship…” The post-modern movement is not new and in fact “family practice, in all its manifestations, began in the 1960’s, a decade of broad challenge and change” (Imber-Black, I, 2014, p.372). Prior to the 1960’s, Bowen and Bateson recognized practice was individualistic, focusing on one person and most often looking back, in “problem saturated monologues”. They knew that people do not operate outside of relationships and most particularly family interactions, which are of paramount influence in people’s lives. Borrowing from family practice, with a focus on the interrelationship between family members, collaborative practice took the theory a step further, in emphasizing the inter-relationship not only between families, but also of critical importance, between family and therapist.

The family practice shift began with Carl Rogers, a pioneering therapist in Person Centered and relational practice. “Over the last forty years, researchers and theoreticians have

gradually expanded Rogers …thinking …into a broader concept known as the "therapeutic alliance" (Maramar et al., 1986). The above point is paramount to the evolution of family and thus collaborative practice, both as it relates to individual service providers and our clients, as well as systemically speaking.

Similarly, Minuchin, in his work with inner city families, felt that it is impossible to separate the individual from the context and situation and believes that context is critical as families, and organizations operate within their context. In Minuchin's video taped address, Reflections on Family Practice (2011), he emphasizes how he always remained true to his belief in offering optimism and hope to families, building on their competence. He highlights how he developed his style, borrowing from his colleagues and stepping away from talking in boxes. His art of borrowing from practices, taking the best learning's from across disciplines, such as the Milan Group, the Women's movement and Post-Modern collaborative and narrative. He learned that a language shift was needed, reducing sexism.

Minuchin states he borrowed from Grisham and Anderson's style of incorporating questions, using humour and becoming less assertive. Minuchin saw the benefits of collaborative practice, witnessing, while being with people, seeing the effects of potentializing. His work was critical to the evolution of family practice and maximizing interdisciplinary strengths, versus remaining fixed and married to a method or theory. "Every innovation in the field invited me to borrow and to question. My style incorporated new techniques and became more nuanced." More recently, Sheila McNamee (2009) coined the phrase "Promiscuity with your Methods", which Minuchin may smile at.

Other important work, leading to the evolution of collaborative practice took place through the Mental Research Institute, where the "therapist could learn to speak the

person(s)'s language, in the broadest sense" (Anderson & Gehart, 2007,p. 24). This resulted in unanticipated "theoretical interests and a new practice paradigm." In fact, therapists "became genuinely immersed in and inquisitive about (their) clients' stories" (Anderson & Gehart, 2007, p.25). This paradigm shift became the very essence of collaborative practice, where the "not knowing" philosophical stance, encompassing the inherent values of generous curiosity, mutual inquiry, and "withness of thinking" were critical (Anderson & Gehert, 2007, p. 51). All of the above applies as well, to the utilization of a collaborative model, when looking to inform and certainly to shift systems.

John Shotter was also vital to this shift, with his post-modern, social thinking as he describes, "withness thinking [as] a dynamic form of reflective interaction that involved coming into contact with another's living being…" (Anderson & Gehart, 2007 p. 68). This again highlights the importance of collaborative practice, which shifts to a mutual engagement, working towards common goals, from a non-hierarchal frame of reference. This power and the naming of it is of critical importance and a discussion about power follows in Chapter Three, when discussing nonfinite loss, grief and the stigma that families face when they have a young person with a mental wellness challenges.

Returning to the discussion about postmodern and constructionist principles, one might ask, what does that mean? According to H. Anderson, in the book, Conversation, Language and Possibilities, postmodern is described, "in its simplest form, …as primarily representing a broad challenge to a cultural shift away from fixed metanarratives, privileged discourses, and universal truths…and is characterized by uncertainty, unpredictability, and the unknown". Similarly, constructionists believe that "meaning must be seen…as the co-production of speaker and listener, where both share in the same active power of linguistic competence"

(Meuller-Vollmer, 1989, p. 14). As will be emphasized below and in the coming chapters, Meuller-Vollmer's quote is of great significance in detailing the what of collaborative practice.

The How of Collaborative Practice

The what, who and when of collaborative practice has been discussed. The question remains *how* is it used? *How* does it happen? If it is a philosophy of life and a "conversation", where techniques are not used, then perhaps it can take place with anyone, and a therapist or skilled negotiator within an organization are not necessary? This raises the questions, what are the components that allow for genuine inquisitiveness and open, respectful, non-judgemental collaboration? How does a therapist or organization, remain neutral, non-hierarchal, and "not- knowing" and co-create a sense of withness? What does it mean to embrace the above and connect with "a person who is feeling pain and anguish in the moment" (Cohen & Bai, 2007, p. 4). Further, what does it mean to have meaningful collaboration between government agencies, or between organizations, where differing agendas are at play? Ultimately, how does one "integrate practice and philosophy, into the meta-dimensions, [which are] the in- the -moment expressions of feelings and attitudes that are reflective of [one's] most deeply held values and beliefs?" (Cohen & Porath, 2007, p. 10). These questions above are ones I hope to explore in the ensuing paragraphs and chapters below.

Reflexive Questioning

The answers to the above questions are multi-faceted and deeply layered. There are many ways of being that allow for the above to take place, although it must begin with the therapists or organizations "willingness to allow [the] person to feel his pain and the person's willingness to allow himself to finally feel his pain" (Cohen & Bai, 2008 p. 9). Again, in the case of an organization, it is about the willingness to remain open, curious, yet transparent and deeply committed to working "with" versus "against".

When the above is present, the therapist may borrow as Karl Tomm (1988) has, from the Milan groups' model of reflexive questions. "Reflexive questions are asked with the intent to facilitate self-healing in an individual or family by activating the reflexivity among meanings within pre-existing belief systems that enable family members to generate or generalize constructive patterns of cognition and behaviour on their own". Reflexive questions, with respect to an organizations' collaboration, may also elicit new meanings, explore beliefs and values inherent in the group and enable participants to generate mutually satisfying goals, to move forward.

As with meaningful collaboration, within questioning there must remain a stance or attitude of authentic neutrality, and lack of judgments, within a relationship between family and the team or interviewer, where, with permission, "questioning will invoke a new and different answer that will prompt new questions, all of which will create a hopefully wider and more elaborate picture for them and [the interviewer]" (Andersen, 1987, p. 3). The same stands true for organizations, as a whole, seeking to "invoke a new and different answer that will prompt new questions… etc."

It cannot be overemphasized that collaborative therapists and/ or participants, whether individually or as an organization must come from a truly non-hierarchal place, constantly

seeking permission to ask questions," that are not focused on discovering information and collecting data" (Anderson & Goolishian, 1988, p.383), but to assist in helping a person(s) [or group] delve into their inner thoughts. Permission is sought not because it is a technique, but because it is respectful and honouring and "are geared toward maximum production of new information".

Reflexive questioning and reflections brought about by the questions, brings into the room, from family, therapist or organization, the relational aspect, creating a curious, speculative witnessing of similarities, differences and hypothetical musings. The circular nature as well as the variety of questions is important. Reflexive questions are most importantly future-oriented to "cultivate [individual] goals: collective goals, personal goals or goals of others" (Tomm, 1987, p. 6). In addition to future oriented, other types of questions look at "observer-perspective, unexpected context-change, embedded, normative-comparison, distinction-clarifying questions, as well as introducing hypotheses and [lastly] process-interruption questions" (Tomm, 1987, P. 6).

The above types of questions, utilized in congruence with a collaborative philosophy, can greatly enhance and draw attention to patterns of behaviour. Tomm (1988) suggests the use of questions for "loosening fixed patterns of perception and thought", for example, "When she takes your sister's side, what does your father do?" Or, "when your organization engages with us, what benefits occur?" The circular nature of the assumptions or questions are also key and "tend to be associated with holism, interactional principles… and neutral attitudes…" (Tomm, 1988).

The "not-knowing" stance is also critical to the how of collaborative practice. "This is not a ruse, not a manipulation: this [is] a position of understanding, a position where one

[does] truly not know" (Kinman, 2009, p.5). Kinman's article honours the work of Lynn Hoffman, who speaks about how she "cherishes each unfolding, each emergence. She treasures all these things as gifts…" Lynn Hoffman's work highlights the moment-to moment interaction, with attention to the "gifts" each person brings with them. That is how, when coming from a collaborative stance, we see people; all people, with an abundance of gifts; people's library of competence (Meuller- Vollmer).

Why Use Collaborative Practice: Its Merits and Applications

All of the above leads naturally into a discussion around the why of collaborative practice. This question is important as we, collectively must, in my opinion, believe in and be intentional with collaborative practice, as it pertains to a deep sense of ethics, as described briefly above. To be ethically engaged, with a philosophy of life, a "stance", then it stands to reason we would not simply "do" collaborative practice, but are compelled, from within to engage "with" this practice.

The why thus flows naturally as collaborative practice offers hope, possibilities, options, and personal empowerment by bringing to light inner resources, strengths and pre-existing competencies that perhaps the person(s) or organization was unaware of or had simply forgotten about. Not only does collaborative practice focus on strengths and resiliencies, it is relational in all aspects, which is proven to enhance therapeutic outcome. In fact, as researchers (Lampbert,1992) indicate, therapeutic relationship accounts for 30% of a person(s) outcome, regardless of technique. It stands to reason that the 30% positive outcome

may also apply across organizations, who practice authentic, meaningful collaborative practice, as relationship is at the center.

In addition, to the aforementioned, collaborative practice also helps create a new multiple- perspective lens, leading to increased hope for present and future possibilities. It "co-create[s] relationships of *enough safety*,… [from] a stance that drives, sustains and invites continuing development,… [utilizing] ever transforming questions.." (Reynolds, 2010). Inviting hope and optimism leads to another key factor in treatment outcome, "the placebo effect". Hope, or the placebo effect is proven to account for up to 15% of desired treatment outcome (Miller & Hubble, 1997).

Further, collaborative practice "create[s] a space for, invite[s] and foster[s] conversations and relationships [to] connect, collaborate and construct with each other" (Anderson & Gehart, 2007, p. 54). Similarly, all of the above regarding the "placebo effect" may also apply and account for up to 15% of desired "outcomes" (Miller & Hubble, 1997) for organizations, as a whole, although as the research into organizational, cross-system collaborative practice is limited, more research is needed.

Additionally, in support of the reason why collaborative practice may be key to creating more positive outcomes for all, and in shifting systems to work better together, with and for families and their children and youth, the research to date does show that collaborative practice can be used with men and women, across situations and issues. It can be used to "[meld] family systems, concepts and practices within complex larger systems, including medical (Doherty, McDaniel, & Hepworth, 2014), family court (Emery, 2014), foster care (Lewis, 2011), child protective services and mental health agencies (Madsen, 2014, Madsen &

Gillespie, 2014), prisons (Baker, McHale, Strozier, & Cecil, 2010) and immigration (Falicov, 2014) (Imber- Black, 2014, p. 373).

As evidenced above, the "stance" of collaborative practice and its cross-sectoral and cross-"issue" application is truly a philosophy of how we view people. Moreover, the ethics of collaborative practice pertains to our own "ethics, which are not fixed and static, but fluid and living. We breathe life into our ethical engagement by continually being open to new learning and new possibilities…" (Reynolds, 2010, p. 24).

In terms of ethics and accountability, "the history of collaborative practice attests to its effectiveness, [which as mentioned above is limited and] has focused mostly on anecdotal and based in qualitative research" (Anderson, 1997, p. 56). By inviting person(s) accounts, from a research framework, it speaks to the philosophy behind collaborative practice and highlights the congruency of the practice with the methodology.

One final note about the appeal and the need for authentic and meaningful collaborative practice is how it evolved from a social justice perspective within the feminist movement. Gilbert (1980) discusses four components of feminist psychopractice, which are all in alignment with collaborative practice. "Practice is about exploring attitudes and values, in an egalitarian practice/client [or between agencies] relationship" (Bankart, p. 368-369).

Not So Fast….

All of the above indicates the many reasons for collaborative practice, however all of the above is not facile. Even though it sounds like a simple conversation with people, both individually and across systems, it is not a conversation that one could have with anyone. It involves training, ongoing reflective practice and great personal self-awareness, on the part of

the therapist, and certainly on the part of systems and/ or organizations and the individuals within those systems. Much training (in the case of systems) and preparation and common ground with both systems and individuals in therapy, around the what, the how and certainly the why are required before authentic, mutually satisfying and sustainable shifts can take place, that allow for trust and open dialogue.

Additionally, boundless caution is required regarding our inner dialogue or the righting reflex, where we form assumptions about the other's agenda and provide unsolicited advice, believing, or even stating outright that we may know better. Collaborative therapists, and collaborative practice leaders must work hard to practice authentic engagement, with those they are dialoguing with and be mindful of their biases due to culture, sexual identity, sexual orientation and/or "white privilege".

Conclusion

Collaborative practice and all of the above speaks to therapists and systems being present and in relationship with others; offering and inviting truly relational work, respecting, honouring and "being a real, living person to the client [or system], a fellow human being looking for answers to life's dilemmas" (Bankart, 1997, p. 369). The above highlights the need for strong congruency with the values of collaborative practice and maintaining an authentic stance of co-creating a dialogical conversation, whereby new opportunities and possibilities may surface. "When we refuse to be co-opted, we continue to teach a new generation to bring a different point-of-view- one deeply rooted in interpersonal justice and family community well-being" (Imber-Black, p. 378). To not do so, we, collectively run the

risk of continuing to maintain the status quo, whereby there remain serious challenges in supporting children, youth and their family's mental wellness.

In Chapter Three I will discuss current system issues, which prevent or prohibit young people and their families from accessing desperately needed mental wellness support and services. Additionally, not only does the mental health care system not fully support families as a whole, I will highlight how the floundering system leaves many families to face their shame, blame and stigma of raising a young person with a mental wellness challenge, to do so, much of the time, alone. In other words, families experience the added burden of stigma and unrecognized nonfinite loss and grief. In Chapter Three I will explore, in detail the issue of nonfinite loss and grief and how, through meaningful, authentic collaborative practice, it holds promise, both individually and systemically to reduce family suffering, leading to greater wellness, for families as a whole.

Chapter Three

Introduction

This chapter discusses in detail to the significant and presiding, invisible, unspoken, and most often unrecognized challenge faced by families of young people who face chronic mental unwellness; I am speaking about nonfinite loss, ambiguous loss and/or disenfranchised loss. All of the above terms speak to how families must continue to adapt and tolerate ambiguity and rebuild their assumptive worlds, (Neimeyer, R., Harris, D., Winokuer, H., Thornton, G., 2011), as families come to terms with their ever-changing reality. I will highlight the what of nonfinite grief and loss and how invisible, disabling, severe and chronic the symptoms can be, for families facing these challenges, with their youth.

The reason for discussing nonfinite grief and loss in relationship to collaborative practice, both individually and systemically is that I hope to highlight this very real issue and as well as the research, albeit limited, related to the benefits of collaborative practice. Additionally, I will provide examples of how collaborative practice may help ameliorate some of the potentially devastating effects of nonfinite grief and loss on family members, including caregivers, siblings and extended family, to the extent that the family is better able to support their loved one, by feeling engaged, empowered and part of the team, versus stigmatized, shamed, and even sometimes blamed and thought of as part of the problem.

In exploring this issue and examining ways of coping, in Chapter Four, I will speak to further examples of collaborative practice and provide specific research behind best practices with respect to family versus professional-led support groups. As parent and author, Karen

Copeland, states in an article on collaborative practice, "authentic collaboration has allowed me to step into the positivity of what's around me, not just the critique" (2016). As I will seek to highlight throughout Chapter Four, in relation to supporting families through their despair and grief and loss; authentic, meaningful, collaborative practice in a group setting may lead to increased empowerment, hope and healing, as well as learning.

Nonfinite Grief and Loss

In outlining specifically the nature of and differences between grief and loss versus nonfinite grief and loss, disenfranchised/ambiguous loss, as mentioned above, it is about examining the ongoing and unfolding process of grief and loss, involving greater awareness, and increased tolerance and acceptance of the ambiguity that nonfinite loss brings, each and every day.

First, I will weave and embed current research and literature on grief and loss, from within a lens of collaborative practice, as a model/ stance and/ or practice, highlighting how individual a process grief is, while exploring the unique and yet *common* ways in which families grieve, when their young person has chronic mental wellness challenges. I will examine how families, as a whole, create and re-create, on an ongoing basis, coping strategies, focusing on what strategies typically work well, and highlighting how important the making meaning process of this ongoing challenge can be.

A Synopsis

Many life events converge to shape who people are, and many diverse factors interplay, forming, informing and shaping our world view. Biology, environment and risk and protective factors all combine to create this unique worldview we all uniquely hold. These

factors also influence how well we, as people, cope with life's challenges. Regardless of how resilient we are, when chronic health affects our young people, whether it is mental or physical health challenges, it is truly acknowledged by research, that these challenges are one of the toughest any parent must face.

To set the stage, drawing from my work with thousands of families over the previous eight years at BC Children's Hospital, families stories are sadly, all too similar. Families with young people with mental wellness challenges, often including and compounded by learning challenges, notice and begin to seek wellness support and/or services, when their children are pre-school aged. Additionally, families reach out to neighborhood house programs, doctors, attend parenting classes, and often seek advice from extended family and friends about how to be a better parent to a child perceived to be eliciting poor behavior.

Often, families are already blaming themselves for doing something wrong with regards to parenting, and often report feeling an incredible amount of shame and stigma for how their children behave. Additionally families of children with behavioral or mental wellness challenges, frequently report that they, as parents, not only, judge themselves; they are also judged, criticized and stigmatized by friends and family. "Stigma refers to beliefs and attitudes about mental health problems and illnesses that lead to negative stereotyping of people living with mental health problems and illnesses *and to prejudice against them or their families*" (Still Waiting, p. 39, 2013).

Moreover, families report that behavioral challenges are often exacerbated in elementary school where children are expected to sit quietly for long periods of time. In early elementary school "these parents" repeatedly receive calls from teachers and administrators

about their child's "inappropriate, disturbing, unacceptable, bad, manipulative, aggressive…ect…" behavior (Copeland, 2015).

To emphasize this point, rarely, if ever has a parent reported to me, that an educator has phoned them about their child's good, positive, respectful, thoughtful behavior, nor do they receive phone calls about their children's *efforts* towards any of these positive attributes. Parents are often asked questions like, "What is going on in the home?, Have you had him/ her tested?", Why might he/ she be acting this way?", and other shaming and blaming and reactive" types of questions.

The unfortunate fact remains that "mental illness affects **1 in every 5 youth** in Canada and, in more tragic instances, may lead to suicidal thoughts or behaviors" (Right By You, 2016), yet despite the statistics, parents experience an immense amount of shame, blame, stigma and guilt when their young person is behaving badly and/or receives a diagnosis of mental illness, or experiences chronic mental health challenges, and these feelings, for parents, translate into "I am a bad parent" (Copeland, 2015).

All of the above and what is to come below, serve as a compilation, and simplification of the thousands of stories I have been honored to be witness to. These stories are the reality of people's lives and represent families from all cultures, genders, sexual identities and preferences; are from rural and urban settings, wealthy and impoverished; new immigrants, refugees, parents with mental health challenges of their own (self-identified), and what a large majority have in common is they feel blamed, shamed and many are experiencing, on some level, whether stated or not, whether recognized or not, is nonfinite grief and loss around what they hoped for in their children, both currently and for the future. Additionally, these feelings of nonfinite grief and loss experienced by families are intensified throughout the young

person's high school years, as stated in the McCreary Centre Society *Adolescent Health Survey* (2013), the challenges youth face, often increase in severity and complexity during adolescence.

Grief and Loss Theories- Past and Present

Before discussing nonfinite grief and loss in relationship to the benefits of collaborative practice, it is important to define the term grief. "Grief is... simply… the normal or natural reaction to loss" (Winokuer, Harris, p. 26). The word *normal* implies a right and a wrong way of grieving and one that follows a specific progression. Current research focuses on the understanding that grief is unique and individual. "There is no right or wrong way to grieve, however….individuals are often expected to grieve in certain ways, based upon gender socialization…and if they do not experience grief in a way that is expected by other" (Winokuer et al, p. 88), they are often judged.

Previous to current research about grief and loss, which now views grief and loss as individual, unique and a "normal process", there were several theories, which still impact current day counseling practice. John Bolby (1980) espoused that "one of the most widely held assumptions about the mourning process is that people proceed through a series of stages as they attempt to come to terms with [a] loss" (Pearlman, Wortman, Feuer, Farber, Rando, 2014, p. 170). Further, "as Jordan and Neimeyer (2003) emphasize, "it is a truism that grief is unique to each individual, yet this wisdom is rarely reflected in the design and delivery of services to the bereaved" (Pearlman et Al, 2014, p. 782).

What is concerning about the above definition is that even when grief and loss, most often resulting from a death, *are* acknowledged, visible and recognized, the supports and services rarely reflect the knowledge about how people grieve. Even more to the point, with

families with young people with mental wellness challenges, most often grief and loss is unacknowledged, invisible, unrecognized and likely unspoken. Families are unsupported in this additional burden, and as mentioned above, if by chance they are able to articulate this trauma, and seek supports, the supports and services, according to Jordan and Neimeyer (2003) are not designed to reflect the current research on how people grieve.

New research not only reflects the growing understanding that grief and loss is an individual and unique process, but also that it does not necessarily follow a series of progressive stages. Moreover, more recent attention about the grief and loss process is examining non-death loss, covering a variety of situations, such as infertility, kidnapping, military missing in action, physical losses, such as loss of limb or loss of the use of limbs, chronic medical and as well as psychological illnesses. As Roos (2002) stated, "chronic sorrow may apply more to those that are caregivers" (p. 103).

The literature on grief and loss employs terms such as nonfinite, ambiguous and/ or disenfranchised (Winokuer & Harris, 2012, p.111-112) grief and loss to describe the non-death losses. These terms have been defined as distinct and separate by Winokuer and Harris, in their book *Principles and Practice of Grief Counseling*, yet to my understanding it is clear that there are many overlaps and in fact the reason for the different terms may simply be due to individual researchers' attempts to coin the phrase for publishing purposes. For the sake of this paper, I will use the term nonfinite loss, which resonates with me and, in my opinion, more succinctly describes the experience. "Nonfinite losses are those loss experiences that are enduring in nature, usually precipitated by a negative life event or episode that retains a physical and/or psychological presence in an ongoing manner" (Winokuer and Harris, 2012, p.100-101; Bruce & Schultz, 2002).

Additionally the non-death loss prevents normal development expectations…physical, cognitive, social, emotional or spiritual, includes the loss of one's hopes and ideals…and has ongoing uncertainty regarding what will happen next. Even more impactful is the "disconnection from the mainstream, [or] normal human experience [and the added anguish of] the magnitude of the loss, frequently unrecognized. To compound the above are significant ongoing feelings of "helplessness and powerlessness associated with the loss (Winokuer & Harris, 2012, p. 101).

All of the above speaks to the significant additional process that family of young people facing chronic and serious mental wellness challenges experience each and every day. As stated above, it is clear that the *normal* parenting challenges people face, which are not easy by any standards, are compounded by the grief and loss around their hopes and dreams of how their family would look like and the negative impact the health challenges have on their youth's future. Further, stigma from society about mental wellness challenges, as well as judgments from family, friends and the community at large; all add to the ever-present and often significant self-blame, which families frequently experience.

Further, the above speaks to the need for therapists, service providers, and systems, as a whole to come from the ethical and value-based stance of collaborative practice, where we, individually, as service providers, collectively are curious, non-judgmental, trauma- informed and most of all strengths-based, as highlighted in Chapter One and Two. Trauma-informed services take into account an understanding of trauma in all aspects of service delivery….., does not necessarily require self-disclosure of trauma….and is more about the overall of the approach, or way of being in a relationship, rather than a specific treatment strategy or method. (*TIP Guide,* p.12, 2013)

Trauma is defined as "experiences that overwhelm an individual's capacity to cope" (*TIP Guide,* p. 6, 2013). Trauma-informed practice (TIP) is, therefore raised and briefly discussed above as the term may be used in conjunction with collaborative practice, as it relates to nonfinite grief and loss, which ultimately is a trauma response, or way of coping with an experience. As is evident, a TIP approach is congruent with and similar to the definitions of collaborative practice, as per Chapter One.

In returning to the above discussion and definition of nonfinite loss, there is an additional concept related to the above whereby Roos (2002) provides a definition of chronic sorrow, which is defined as "a set of pervasive, profound, continuing, and recurring grief responses, resulting from a significant loss or absence of crucial aspects of another living person ….to whom there is a deep attachment……The loss is ongoing … and is experienced as a living loss" (Winokuer & Harris, 2012, p. 102).

The concept of chronic sorrow also speaks to the traumatic effects of raising a young person with mental wellness challenges, and families cannot help but come to us from such a frame of reference. Often, it seems as if we, as therapists or systems presume to judge, assess, and in fact, pathologize the family, when in fact, it is clear that it would be *not* normal if these chronic health challenges did *not* have an impact on a parent/caregiver, let alone the family as a whole!

Collaborative Practice Lens- Almost "Unethical" Not To

As the collective stories of family experiences helps to illustrate, nonfinite grief and loss presents itself in parents, through feelings of inadequacy, shame, and guilt, not to mention

helplessness and sometimes hopelessness. Even early on, when young families begin to recognize that their children have challenges, or perhaps are given an initial diagnosis of learning disabilities and/or Attention Deficit Hyperactivity, and Attention Deficit, Inattentive Type, the gradual realization of the long-term impact is painful.

Families often describe a feeling of numbness, which is not dissimilar to how cancer patients describe their emotions at the time of diagnosis. Again, this numbness is a trauma response, "leav[ing] individuals feeling powerless, with little choice or control over what [is] happen[ing] to them" (*TIP Guide,* p.29, 2013). These trauma responses, and nonfinite grief and loss in families with young people with mental wellness challenges are only just beginning to be recognized, let alone, validated and supported from a collaborative practice and trauma- informed lens.

Trauma Informed Practice (TIP) as defined above, and collaborative practice, as defined in Chapter One, has many similarities, and both come from the stance of offering, choice, collaboration and connection. For the purpose of my thesis, I will refer to collaborative practice as defined in Chapter One, with the understanding that a trauma- informed lens equally applies to this discussion of nonfinite grief and loss, and how families, young people and service providers, individually or systemically must engage dialogically, and authentically with each other in order to co-create new narratives.

Collaborative Family Support Needed To Aid in Trauma Responses

In returning to the discussion about a families' nonfinite grief and loss, what is clearly also of importance, is that families of young people with challenges, as described above, often do not realize, how severely an early diagnosis may impact their lives, down the road. The fact

remains that many families would benefit from a collaborative practice stance, from an individual therapist, where they feel part of a team and not part of the problem. “The positive role that family can play in advocating and supporting the care of family members and the importance of providing support to the whole family,” is paramount (*Healthy Minds, Healthy People, Engagement Summary,* p. 5, 2014).

Ironically, families report that they need support and guidance, at home, from educators, and from the community at large. Repeatedly their efforts to find appropriate funded supports and services, as privately funded options are not economically feasible for many, is difficult, at best, as systems do not collaborate with each other, whereby schools, physicians and mental health teams, most often function in a siloed and fragmented manner. “Overwhelmingly, parents and caregivers….used the terms scary, confusing and frustrating to describe the experience of navigating the mental health service system…..Even a practitioner said, “I still get confused, and I work in [the system]” (Still Waiting, p. 44, 2013). It is no wonder that many families experience ongoing trauma from within and by the system, which perpetuates and exacerbates nonfinite loss. Further, families’ efforts to intervene early, both at home and with the help of professionals is challenging at best, and impossible at worst. As Winokuer et al., (2012) explains “parenting a child with a mental health problem…,[or] mental illness… involves adjusting and coping and is a unique form of grieving that never ends” (p. 102).

In keeping with nonfinite grief and loss symptoms or in other words, trauma responses, families often report that their thoughts and feelings are like a roller coaster ride, and some have used the analogy of a wave, oscillating between successes and highs to failures and lows, where over time, they feel their parental self-confidence erode. Additionally, they witness

their young person's failures, often, first scholastically and eventually socially, whereby, down the road, as adolescents, they are attracted to and attach themselves to those who are emotionally struggling, just as they are.

For families, typically, nonfinite grief and loss is intensified throughout these adolescent years. Parents, as well as siblings and extended family, watch confused, helpless, and sometimes utterly powerless, despite their efforts to remain attached, engaged, loving, empathic and even trusting. Families are truly terrified that their youth may die due to impulse control challenges, which often increase the high-risk behaviors. Despite the ongoing efforts of many parents, they frequently remain judged, blamed, shamed, on top of carrying intense grief and loss about what could/ might have been. "Mental illness can prevent a young person from performing in school or from making friends, and in some instances, may lead to thoughts of suicide. [In fact], as many as 20% of youth have a diagnosable mental illness [and] almost 90% of people who die by suicide have a mental illness, including ADHD, anxiety and depression, ect..." (Right By You, p. 4-5, 2016).

System Navigation Challenges Add to Isolation and Grief Response

Without authentic, meaningful collaborative practice, both individually, working along-side therapists, as well as systemically, working inter-disciplinary, across systems, families, and young people are often shut out. "A number of parents and caregivers were either not offered services….or were unaware of available services" (Still Waiting, p. 46, 2013). Families are truly in the midst of a chronically challenging situation, amidst a system that judges them instead of supporting them. Families feel intense guilt and shame and most often report they hide their struggles from friends, family and the community, trying to be a *normal* family. "Research shows that living with and being the main care provider for family

members with a mental illness can be a source of tension, emotional stress and financial strain" (Still Waiting, p. 44, 2013). The embarrassment and shame… and ultimately the stress, strain and chaos, unfold not only in the home, but also in school and community settings.

Further to all of the above, it has also been suggested that nonfinite grief and loss feels like a wave of emotions, coming often without warning and the resurgence of the grief and loss response ebbs and flows, often violently, depending on the ups and downs of the young person's struggles. As one physician was quoted in the *Still Waiting Report, "* I think there are very few things that are so stressful for family than a child who is psychiatrically ill, [the] stigma, [decreased] family functioning, future outcomes…it must be one of the highest levels of stress there is. They are dealing with it 24/7…."(p. 44).

Despite all of the above, it is not only surprising, but also perhaps negligent that families are not offered family counseling within government funded Child and Youth Mental Health. Young people, especially in adolescents are seen almost exclusively, individually, which highlights one family members' problem versus focusing collaboratively and within a relational context, to explore the system as a whole, from a strengths based lens. As one mother stated, "I know [my daughter] is struggling, and as a family we bear the burden of dealing with it, but we are kept in the dark about what issues she feels she has" (Still Waiting, p. 47, 2013). In order to better support mentally unwell young people; families need knowledge and skills and to be included and empowered to be a part of the team.

Collaborative Practice: An Approach To Empower Families and Reduce Symptoms of Nonfinite Grief and Loss

Through meaningful collaborative practice, authentically offered, families may learn to accept that they are, for the large majority of the time, doing the best they can, with what they have and what they know. Moreover, families, and their young person, who are empowered through being part of the solution, in terms of working *with,* versus in opposition to, can shift and learn new, more effective ways of engaging with their youth, leading to increased relationship connectedness, given the tools. Families, and young people who feel engaged, through collaborative practice, as research shows, are more likely to engage with other community supports and become better equipped to cope. "Parents and caregivers are vital resources for the well-being of an adolescent involved with alcohol or other drugs [and/ or who may have mental wellness concerns and]…hold important …knowledge, …wisdom…and a deeply rooted investment in the long-term health of their [young person] (McCune, p.2, 2016).

Not only is the above increased engagement more likely to happen when people are respected, empowered, offered choice, and feel connected and can trust each other, they report feeling less isolated, less to blame and report increased self-agency and intrinsic motivation towards change. "Those [agencies] providing direct services, to parents and caregivers, [working along-side them, collaboratively] are privy to experiences of surviving and thriving, fear, hope, challenge and triumph" (McCune, p.2, 2016). Families want support. Families want help and are more likely to work on sustainable goals, decreasing their symptoms of nonfinite grief and loss, when feeling included and connected and honored; not judged.

Another benefit to collaborative practice, which may reduce the destructive effects of nonfinite grief and loss, is the fact that families report feeling less stigmatized and more open to share and learn from others. Further, families report feeling greater willingness to open up

to friends and family, teachers and even police officers who may be involved with their young person, leading to greater understanding and support. Further research behind the positive influence of collaborative practice will be highlighted in more detail in Chapter Four, when examining the model of collaborative practice of peer- and professional led family support groups.

Nonfinite Grief and Loss –What Is It?

In examining the benefits of collaborative practice and how it may in fact reduce the traumatic effects of nonfinite grief and loss in families with young people with mental wellness challenges, it is important to understand the process of this particular type of grief and loss. How does the grief and loss process set in? At what point do families, as well as therapists recognize that families are presenting with much more than their young person's mental health challenges. Additionally, as highlighted in this chapter, families are experiencing a grief and loss so profound, so traumatic that the experience can also present as traumatic stress related disorders.

Trauma as previously defined is "exposure to a distressing, emotionally overwhelming experience such as exposure to violence or life-threatening situations…..[such as self-harm or suicidality]…. [As] witnesses of such incidents, loved ones….are at risk of developing trauma and stress related disorders (*Ministry of Health Policy Directions Paper, Draft for Discussion* ,p. 55, Oct. 8, 2015).

Related to all of the above, many questions relate to how families truly experience the intense shame of feeling embarrassed by their young person's behavior. At what point do families feel that their family is not *norma*l? How long does it take before parents wonder if

these challenges are their fault, and even worse, wonder if they have failed as parents? All these questions are ones that families have wondered aloud, to me.

Families agonize over these and other questions, and try to process them; yet these questions repeatedly re-surface, along with the never-ending feeling of grief and loss, as yet another challenge, relapse or setback, happens. All the sorrows of what could, should, and still might be, come to the surface, each and every day, for the vast majority of families who shared their stories with me. "There are times when grief that has abated in its intensity over time can be reactivated in a very real and intense way. Most commonly, these resurgences occur at significant times, such as a graduation, or at special family times…"(Winokuer et al, 2012, p. 87). The pain and grief and loss is especially sharp as families report that a friend's son or daughter graduated from university or travels around the world, or is hired in a job that is the start of a career. Nonfinite grief and loss is constant, and families need help in recognizing the symptoms and understanding how to cope. Collaborative practice is a first step.

Nonfinite Loss and The Stigma of Mental Illness

Further to all of the above, in later high school, after many years of struggles for a young person, families often report that a second or even third diagnosis may result. The stigma of these often more severe illnesses such as Obsessive Compulsive Disorder, Conduct Disorder, Bipolar Disorder, Schizophrenia, or Borderline Personality Disorder (DSM 5, 2015), are devastating. Surprisingly, these additional diagnoses may not result in additional support and help. Often repeated hospitalizations and police interactions take place and families are left not knowing how to manage, nor cope.

I have frequently heard from families, *and* service providers that "he/she is just wanting attention" or "they are borderline and all borderline's say they will kill themselves." These judgments about adolescents, in particular are extremely disturbing to me, and certainly would contribute to a young person's lack of engagement. It is devastating for families to be faced with a young person in such real and evident pain, yet remain at a loss for where to go for help or support for the family. Additionally, families continually report feeling under great scrutiny from professionals providing support. The statements I was witness to, via families, or with families, such as, "You are making your daughter a scapegoat for your own issues", or "I see you are a very involved mother and your son is now 19…he is an adult". There are few words to describe how the stigma added to self-blame, compounds a family's intense feelings of nonfinite loss.

Additionally, as children become young adults, over the age of 19, the lack of collaborative practice approaches, including how young people are transitioned to adult mental health services and supports, are detrimental to all concerned. In the 2014 report, *Healthy Minds, Healthy People,* one of the eight dominant themes "identified [as] priorities to guide the next three years of the *Healthy Minds, Healthy People* ten-year plan [is] "transition points", with a particular emphasis on youth transitions" (p. 5).

As mentioned above, families feel immense financial as well as emotional burden throughout the many struggles and setbacks of their young people's lives. It is important, however, to note that there are also stories of success. In relation to nonfinite loss, as parents or caregivers, successes, which are often small compared to the *norm* of young people their age, are celebrated. To families, these successes are enormous. To outsiders, it appears as if the bar has been lowered to celebrate a return to school, or a pass versus a fail. Despite these

and many other chronic challenges, most families keep going. Despite the many challenges, most remain proud and humbled by their young person's courage. I, too, working in the field, am honored to continue to witness family's strengths, and I am grateful for all they, collectively have taught me about resilience and acceptance.

The above ties in well with the fact that for families, the often chronic sorrow associated with all of the above, and what I will outline below is certainly at the root of nonfinite grief and loss. As research demonstrates, there are many coping strategies to manage nonfinite loss, including maintaining hope for the future, while living with acceptance of what is, however without acknowledgement, recognition of this issue, there is little likelihood of support for families, as a whole. Again, collaborative practice, with a stance of open, curious, acceptance, is a place to start. For organizations, collaborative practice is also the key to creating new possibilities, and learning from each other.

Nonfinite Loss: The Double Edged Sword of Guilt and Gifts

Writing the above negative impact statements leave me feeling somewhat guilty about what I have presented thus far with respect to the collective stories about nonfinite grief and loss. I want to make clear and reiterate that many families remain so very proud of their children. They highlight how each young person is unique and each has so many strengths and gifts. As parent and author, Karen Copeland in her blog post titled, *I Am That Parent"* (2015), states so eloquently, she is proud of her son, and of herself too. Instead of feeling embarrassed about all that "goes awry" for her son, she states below,

> *I would love to tell you that I am proud of my son and his courage in facing each day. I would love to tell you how I am proud of myself for becoming more knowledgeable about the challenges my child faces, learning about the systems we access for support, learning the jargon so I don't feel dumb*

> *sitting at the meeting table when an acronym is used…..Unfortunately, I am not asked.*

I continue to be in awe of the incredible and enduring resilience, many families demonstrate in the face of so much adversity, and for many, despite experiencing nonfinite grief and loss, family's regularly report that their young people continue to be their greatest teachers. Families learn patience. They learn to listen to their youth and also learn to listen to their own intuition. They learn they cannot fix. They learn the art of more effective communication and ultimately, offer true, unconditional love. In fact, they often learn what true empathy *feels* like, both for their children, and towards themselves, through greater self-compassion.

Conversely, and in keeping with the premise of this thesis, many families also learn what all of the above is *not.* What I mean is, families report the opposite of learning, and being listened to, and instead report being told what to do, and certainly experience the feeling of not being listened to, about their thoughts or feelings regarding their young person. In other words, families, for the most part report a strong lack of collaborative practice, both individually and systemically speaking. "The lack of parent and caregiver involvement in planning seems to be the result of a number of factors…..[for example] parents talked about …the assessments and treatment options [made] without [even] consulting families to understand how the youth is functioning day to day…." (*Still Waiting,* p. 47, 2015).

The above is so detrimental to family wellbeing, as a whole, and so rampant that I doubt I would have had the job that I had, over the previous seven years, if meaningful collaborative practice was in evidence across systems. Further, if this significant and alarming gap in the system didn't exist, I would perhaps not even be at City University, feeling the need

to continue to shift systems, which truly is my passion and why I chose to write about collaborative practice.

One "practice example, *the Families Matter Framework for Family Mental Health in British Columbia,* [which was] funded by the government of B.C. and developed by the F.O.R.C.E. …Society…" (*Still Waiting,* p.47, 2013), is a case in point. Through working with the F.O.R.C.E. Society and witnessing thousands of families struggle with child and youth wellness, as Chris Kinman (2004) states, as per Lynn Hoffman, the gifts they have given me are priceless.

Before elaborating on further factors that influence nonfinite grief and loss of families with unwell young people, I will discuss the influence that all of the above has on mothers specifically, as unfortunately gender is still an issue when it comes to parenting blaming and shaming. To be a parent of an unwell young person is very difficult. To be a mother, of an unwell young person is often far more challenging. Society, researchers, as well as the community, as a whole, look first to the mother, when children are struggling, as per the "Refrigerator Mother's Theory" (Kanner, 1943; Jack, 2014). Mother's often wrestle with strong feelings of responsibility, confusion, chronic sorrow and certainly grief and loss. These intense emotions live inside many mothers, as reported to me, and unfortunately, mother blaming is common to this day. The underlying questions and assumptions around young people's mental wellness is still, "What happened? This type of question implies a certain level of blame. What was missing? What was the cause?

My questions are, "How can families (including and perhaps especially mothers) be empowered, and have an open dialogue and be brought into being part of an integrative team, when there is an underlying elephant in the room that there is a reason for this dysfunction?

The language of a biological/ medical model and mental health diagnoses *is* stigmatizing. The language of counseling, a psychosocial model can *also* be stigmatizing. “The question, “What happened?” implies something went awry. Again, how can we ever hope to support and empower the young person with the illness, if at the same time we disempower the parent/caregiver, and all too frequently, …… the mother? This piece of the puzzle is one I ponder, fight for and speak against in the work I do every day. I ask you to ponder these same questions.

Perhaps there is no answer to the above, however here is what I *do* know. When a child or youth is diagnosed with a serious medical condition, families are supported and sought out and consoled. Families of mentally unwell young people are, frequently ostracized, as no one speaks about what is going on and few families self-disclose the reason for the “ bad behavior”. In fact, in mental health treatment, families are often not included in treatment decisions and are unknowingly, psychologically assessed, along with the young person.

Further, in community, families are frequently not invited to social situations, due to the behavior of the child, leaving families feeling physically and emotionally, even more isolated. It is not uncommon for clinicians, and even co-workers to judge the parents in how they engage with their youth. Family and friends frequently offer unsolicited advice. It is surprising to me that many families do not also experience severe depression due to the chronic stress associated with all of the above. I am unsure on the statistics related to depression in family members of young people with mental wellness challenges, however as it is beyond the scope of this thesis I will not explore this further. The above would be a worthwhile area to explore when examining the positive effects of collaborative practice, in terms of caregiver and family wellness as a whole.

Shortly, I will discuss some suggested ways of coping and examine the current literature on grief and nonfinite loss. Before doing so, I need to re-count further exacerbating and compounding issues which may add to and deepen nonfinite loss. What I speak of is complicated grief, "a condition that is painful and impairing…(Neimeyer et al., 2011, p. 135). Given the accumulated losses and the ongoing nature of family's guilt, this may also be something to explore collaboratively, in terms of family support.

Compounding Concurrent Disorders and Nonfinite Grief and Loss

As described above, adolescents can be one of the most intense times for families, when youth may be experiencing an emerging mental health crises resulting in a diagnoses, presenting as intense mood swings, ongoing life threatening situations including self harm and acute suicidality. "Three times as many youth [between the ages 15-24] die by suicide than all forms of cancer combined" (Right By You, 2016, p.5).

Siblings may also be struggling given the severity and chronicity of their brother/ sister's illness. The influence on siblings is also frequently ignored or simply unrecognized. Often, at these times of heightened crisis, adolescents may begin to self- medicate, or increase their efforts to self-medicate, with alcohol, cannabis and/or other illicit substances. Further, young people, "aged *twelve or under* who used marijuana, [are] 40% [more likely to have done so], [because of] a health condition or disability, (*Blunt Talk,* p. 18, 2016). Also of note is that "youth with mental health challenges were more likely to have used marijuana on most days in the past month… (19%)….than those without a [mental health condition] (10%) (*Blunt Talk*, 2016, p.13).

Families are likely unaware of all the specifics of the young person's substance use, however families are understandably concerned, given the heightened situation and/or crisis, due to the mental health challenges. Fortunately many youth are candid (or scared) enough to disclose their escalating use, especially when symptoms of their use become alarming to them. This may be the case when symptoms of paranoia, (which may indicate a drug-induced psychosis, defined as "a serious mental health condition in which a person loses touch with reality through distorted perceptions or hallucinations…and disrupted thinking or delusions…(*Establishing a System of Care for People Experiencing Mental Health and Substance Use Issues,* p. 55, 2015). Psychosis can be scary to witness and, as parents report, they know something is not right, yet are unsure what is happening at that moment. "Youth, parents and caregivers cited their own lack of understanding of mental health, as a barrier to getting help. [Further], some considered people with mental health problems to be "crazy" and …..feared stigma if others learned they were getting mental health services" (*Still Waiting, p. 39, 2013).*

Additionally, parents worry about not only their young person's illness, but substance use as well, which again, only increases the severity of the impact of these challenges, negatively impacting further, the symptoms of nonfinite grief and loss. No parent is prepared for their young person to be mentally unwell, nor addicted to substances. The above situation is heart breaking and we can assume only adds to parents' feelings of hopelessness and helplessness.

As research demonstrates, when young peoples' efforts to self- medicate with substances, to reduce the symptoms of an anxiety disorder, for example, this attempt to cope, often leads to further negative consequences, not only to their health, but with the school

attendance and even the law. When the substance use is severe enough, young people are not physically well enough to attend school, nor do they have the motivation. “74% of youth who used marijuana on 20 or more days reported skipping class.…[Additionally], using marijuana on most days [is] also associated with lower levels of community connectedness, and 32% of youth who [have] stayed in a custody center first tried marijuana before the age of 13 (vs. 10% who had never been in custody) (*Blunt Talk, p.25)* . Further to the above points about co-morbidity with substance use, including alcohol, and other substances, as well as marijuana, “youth who [have] a mental health condition were more likely than their peers to [use] marijuana because of stress (47% vs. 20%) and because they felt down or sad (39% vs. 10%) (*Blunt Talk,* p.38, 2016).

Further to all of the above, which paints a dire, and alarming picture for parents and caregivers, of untreated or ineffective treatment of wellness challenges, parents become so desperate, and so grief stricken that they often attempt to force their young person to attend a residential treatment center. This too, creates stress and grief and loss as the family is torn apart. Further and unfortunately, unless the young person is in a place of readiness to make a change, the substance use likely re-commences upon completion of treatment. Additionally and of compounding consequence to the young person, is the fact that 47% have mental health challenges which go largely unaddressed in treatment centers across B.C. and Canada. Due to all of the above, many youth with “concurrent disorders” do not complete high school graduation requirements.

Understandably, this fact, contributes further to a family’s source of chronic sorrow. As evidenced, a family’s loss of hopes and dreams for their young person’s future is chronic and ongoing. Often too, the young person uses such gateway drugs as cannabis to delve into

even more addictive substances like Fentanyl and even Heroin. "Youth who had been using marijuana for more than a year were also more likely to have tried alcohol and other substances, such as cocaine, hallucinogens, and amphetamines" (*Blunt Talk,* p.28). All of this as well as the fact that "youth who knew someone who had attempted suicide (family member or friend) were more likely to have used marijuana on 20 or more days in the past month (13%). Many other risk factors such as poverty, refugee status, identifying as LGBTQ2S, and those experiencing victimization, all too influence substance use, however again, that discussion is beyond the scope of this paper, which seeks to address the dramatic and devastating effects that nonfinite grief and loss plays in relation to child and youth wellness, and how meaningful collaborative practice may help alleviate some of the effects of nonfinite grief and loss.

Lastly, and of significance to a families ongoing grief and loss and chronic sorrow related to nonfinite loss, is that all of the above, often at it's most severe, may contribute to a family's marital breakdown, (Neimeyer et al., 2011, p. 85). This marital breakdown consequence, often in particular, related again to the mothers, puts them within the parameters of Umberson et al., 1992's research, whereby they likely experience significant "decline in economic well-being [due to separation and divorce which] triggers anxiety and distress." Additionally, mothers of young adults, today, are far more likely to be a part of a "current cohort of … women who…[primarily] tended to child-rearing and family responsibilities …. [and] have fewer years of paid work experience and lower earnings than [their] male counterparts" (Neimeyer, et al., 2011, p, 85). All of the above greatly adds to the impact of nonfinite loss on a family as a whole.

Accumulated and Complicated Grief: Instrumental "Style" of Grieving

As the above will attest to, there is no doubt that accumulated grief, as well as trauma has been a part of a parent's process over the course of raising a young person with mental wellness challenges. Many parents, in particular mothers, in my opinion, may also fit the criteria for a diagnosis of complicated grief? Further, a family's unfolding "…trauma and multiple losses (Gamino et al, 2000; Neimeyer, Harris, Winokuer, Thornton, 2011, p. 140), [likely] lead to substantial impairment in health and quality of life". Such "impairments perceived or present in family members, and parents in particular, would seem an appropriate and natural response to the significant and multiple co-occurring losses" (Neimeyer et al., 2011) that many families face, given the above scenarios.

It angers me greatly to recognize just how much many families withstand, being assessed, pathologized, and often unsupported, and despite this known fact, continue to reach out and access supports and services, both for themselves and their unwell young person, despite the blame, immense sense of shame and stigma, and despite their sometimes disabling nonfinite grief and loss. "Targeting all British Columbians…..services [must be] designed to build the capacities of individuals, and families, to improve their ability to cope with adversity, and to create supportive community environments (*Establishing a System of Care*….,p. 34, 2015).

The above highlights the complicated nature of many families grief and loss and how the "psychological consequences of any one stressor may be amplified when experienced in conjunction with other losses or strains" (Neimeyer et al., 2011, p. 85). As evidenced by recent research there are several grieving styles proposed, ranging along a "continuum from intuitive to instrumental." A critical piece of these proposed styles are that "the differences in

these styles are in the ways an individual *experiences* grief as well as the way grief is *expressed.* …These styles affect the ways an individual *adapts* to his or her loss*"* (Neimeyer, et al., 2011 p. 71). This is clearly evident with individual family members.

For example, "the intuitive griever will more likely focus on their emotions, in the realm of the affective domain, as opposed to the instrumental griever who tends to focus on their intellectual understanding of the loss, remaining mainly in the cognitive domain" (Winokuer, Harris, p.84, 94). How families are able to express their grief and loss is greatly influenced by their natural inclination towards the cognitive or instrumental style of grieving. Some people gravitate towards the primary adaptive strategies which is very much in the doing of grieving. This style is indicative of those parents who seek out as much knowledge on the diagnosis or illness of their young person, such as learning about Attention Deficit Disorder, learning disabilities, substance use, self-harm and/or suicide, to name a few.

Further, family members often research options for support and services. They seek out ways to advocate for supports when they experience system gaps. Sometimes family members pro-actively seek out supports for the whole family, and in some cases, when they feel they are truly desperate for help, they write letters to the Premier, the Ministers of Health and Children and Family Development, or take their pleas to the media, about the issues and gaps in the mental health care system. "Mental health services are fragmented, difficult to navigate, and too often do not support and involve families in caring for youth who are experiencing mental health problems" (*Still Waiting,* p. 86, 2013). This situation is not rare. In fact, sadly, these experiences are the *norm,* as the system has been failing families, as well as young people.

Recent Collaborative Practice Policy and Strategy Unfoldings

This is why a meaningful collaborative practice stance is needed, wanted, highly warranted, and currently, slowly unfolding in British Columbia, as well as all across Canada. Examples of this collaborative shift, this ground-swell of attention to the service design and delivery have been mentioned above, in the work that the Mental Health Commission of Canada's, *Ten Year Plan* has outlined, in addition to the *Healthy Minds, Healthy People Engagement Summary*, 2014, the B.C. Representative for Children and Families, *Still Waiting Report,* 2013, not to mention the recommendations made as a result of the B.C. Select Standing Committee on Child and Youth Mental Health in BC, 2013, 2014.

The above are just a few of the many policy documents and recommendations, co-created, collaboratively with families, and youth with the goal of shifting a failing mental wellness system, alleviating some of the burden on families who are required to manage crisis after crisis alone, and creating an environment, where in many cases, families as a whole are unsustainable (Gottman, 2004), given the ongoing trauma, of an mentally unwell youth, leading to worsening parental nonfinite grief and loss, to name only one such consequence.

An example of one organization that is working collaboratively with the system, as well as individual service providers, enhancing family well-being, as a whole is the F.O.R.C.E. Society for Kid's Mental Health, now known as the FamilySmart Intsitute of Families, DBA. The F.O.R.C.E. in BC. The F.O.R.C.E. collaboratively provides support, guidance, and system navigation for families across British Columbia, and also teaches advocacy techniques, when needed. There are fortunately, many more examples of meaningful collaborative practice underway in B.C., such as the VCH Family Advisor Committee, which

in 2013, co-created a family support and involvement policy. Additional examples of collaborative best practice throughout B.C. and Canada will follow in Chapter Four and Five.

Intuitive and Blended Grieving "Styles"

Further to nonfinite grief and loss and how families cope, in addition to the instrumental style of grieving mentioned above, which is the doing style, there is also the intuitive style of grieving; where a person is acutely aware of and allows in the feelings of sadness and vulnerability, guilt, regret, and fear. Often this "spontaneously express[ive] [style shows up through the expression of] painful feelings through crying and [wanting] to share inner experiences with others' (Neimeyer, et al., 2011, p. 71). In addition to the above two styles of grieving, there is the blended style, which allows both the "head and the heart" (p. 72) to connect. This balance in head and heart, in how one experiences emotional pain is perhaps the most healthy and effective way to process the ongoing nature of mental wellness challenges, the ups and downs, that present themselves, and is at the very core of nonfinite loss.

Coping with Nonfinite Grief and loss: Meaning Making / Meaning Re-Construction and "Normalizing" Through Systemic Collaborative Practice

There are many evidence-based practices or interventions to support people experiencing grief and loss. Nonfinite loss is not unlike the experience of grief due to a finite loss (death), however the ongoing and ambiguous nature of nonfinite loss may in fact be more difficult as it is never-ending. First, naming the feelings as grief and loss, as opposed to depression may be very helpful, in that it acknowledges the loss. Grief is very much alive as

per families self-reported experiences, in that they are actively experiencing the ups and downs. As one parent quote describes the experience, “I think about what a roller-coaster we live on with our kids in their struggles in life. Sometimes it is up and sometimes it is down, it’s all over the place! We are up and we’re down, as parents, and it takes its toll on us too” (McCune, p. 2, 2016). Conversely, depression, as stated by Rando (1993), is more about a feeling of “numbness” and “static moods and feelings”, which can be a very different feeling than grief.

Another strategy, which is proven extremely helpful, and is one I will discuss in more detail in Chapter Four when speaking about collaborative practice and family support groups, is the process of normalizing the ongoing nature of a family’s loss. By understanding that “[families] inabilities to resolve [their ongoing] feelings of grief is not due to personality deficits or deficiencies, but due to the situation that has been created by [nonfinite] loss” (Neimeyer, et al, 2011, p. 243), it has been repeatedly reported to empower and make sense of the despair.

As the research also indicates, and again will be discussed in Chapter Four, finding and utilizing social supports, especially peer based and collaborative models, is key to reducing family’s sense of isolation and grief and loss. As one service provider states in a quote, “What has perhaps been one of the most inspirational aspects of my work as a counselor is witnessing the grip of isolation being released through the act of engaging with another human being in conversation” (McCune, p. 10, 2016).

When families do reach out for support and are offered meaningful collaborative conversations, it truly is magical, as one counselor, reports. “When absolute strangers connect through the similarity and uniqueness of their stories, something profound happens on such a

basic human level. There comes a moment in a [collaborative approach to a family support] group when belonging, significance, acceptance, and compassion come to life and in an instant people's world's change" (McCune, p.10, 2016). When families feel supported, listened to, validated, empowered, and experience a sense of shared sorrow, their ability to cope is significantly enhanced.

Maintaining Hope and Building on Strengths, Amidst Uncertainty

The double-edged sword is that on the one hand, families must gain the courage and strength to reach out, despite often feeling judged, shamed and blamed, and when they do, it is very challenging to find the right help. This is key. The right help is, as mentioned, a collaborative, meaningful, non-judgmental, validating, empathic helper. The above describes the collaborative stance and ethics that are paramount to support for families, where they are recognized, acknowledged and supported in their grief and trauma responses. Unfortunately, currently, from all accounts, this type of help can be difficult to find.

Another helpful strategy to manage the strong and ongoing wave of emotions is to learn to shift one's lens to what *is*, as opposed to what is *not*. "By focusing on the innate strengths, within [us] as well as within [our young persons], [families] can more easily "identify what is not lost" (Neimeyer et al., 2011, p. 243).

Through a process of meaning making and purpose, families can keep going. Often we see this in advocacy work from within family organizations, such as the F.O.R.C.E. Society, The Kelty Patrick Dennehey Foundation and Jessie's Legacy, to name just a few. In essence, these organizations have been " facilitating the integration of [their collective] loss" (Neimeyer et al., 2011, p. 154) by working with families who are dealing with similar

challenges. All the above organizations work collaboratively with families, and importantly, with mental health professionals and researchers to co-create supports and services and enhance the effectiveness of existing programs to better serve those seeking supports.

For example, The Parent Guidance Program, at CSU- Columbia University, is very similar to the work being done at BC Children's Hospital, Kelty Mental Health Resource Centre. As Neimeyers at al., (2011) states: "The goals of the [program's] interventions [are] to educate and empower [families] with knowledge of their children's stresses…. and support the children's coping to encourage and enhance empathy between family members" (p. 206). Therefore…"people are not seen to be objects to treat, or causes of distress but are competent and capable resources for their family member's recovery" (Seikkula & Olsen, 2006) (McCune, p. 12, 2016). People are seen as individuals, with unique challenges and requiring support, guidance and most importantly empowerment.

Self-Care and Coping Strategies: What Else Works to Help Alleviate Grief and Loss Responses

Coping tools are "activities and strategies that comfort, calm, soothe or support and individual" (Pearlman, et al., 2014, p.170). Families actively employ many strategies to help them in their journey. Too often, when in chronic stress, families may develop unhealthy "coping, such as substance use, blaming and shaming their young people as well as many other unhealthy coping" (Pealman, et al., 2014). Research shows that by identifying my values and setting personal goals, they "both reflect and provide a sense of purpose and meaning" (Pearlman et al., 2014, p. 185).

Of course, it is of paramount importance that service providers are also aware of self–care to be able to work most effectively and ethically with families, such as "engaging in self-care and pleasant activities, breathing… using social supports and addressing automatic thoughts" (Pearlman et al., 2014, p. 170).

As mentioned above, despite the ongoing nature and ambiguity of nonfinite loss, there are many gifts families may gain from a situation. Through the process of nonfinite loss, families report much growth. "Times of great pain and despair are also times when we identify what is most important…and when we also recognize positive aspects of ourselves that we may have never known before" (Neimeyer et al., 2011, p. 243.)

Families may learn to tolerate increasing levels of ambiguity, and in fact, temper mastery of ambiguity (Neimeyer, et al., 2011 p. 172). This concept of tolerating ambiguity is what many families with an instrumental style of grieving, find to be the most challenging, as they tend to be "doers". Most families naturally want to fix and make better, and added to this natural tendency, which many people have, due to our society, as a whole, being very much about fixing; families are often forced to "embrace, accept and tolerate a new assumptive world, dialectically, of grieving the loss of what *should* have been *and* celebrating the possibilities of what *may* be" (p. 170). In other words, families with young people with mental wellness challenges must learn to " increase their tolerance for pain *and* increase their tolerance for the ongoing ambiguity", and the ongoing unknown (Neimeyer, 2011).

Relapses, Setbacks and "Holding Space"

There is little end in sight, within the experience of nonfinite grief and loss, other than the maintenance of eternal hope whereby families learn to focus on the small successes, which

are actually huge successes. “Research confirms the importance of hope…as a curative factor” (Miller, Duncan, & Hubble, 1997, p. 124). Families learn, often through the sharing of stories in family-run, collaborative support groups that they can remain in a state of hopeful optimism, in the face of adversity and failure.

The above holds true for families that report the repeated efforts and relapses of their young people, with regards to any number of forward moving choices, such as returning to school or university programs, remaining “clean” after the completion of a substance use treatment program, or perhaps experiencing ongoing challenges with their young adult intimate relationships. There are literally thousands of examples like these where families learn to hold space amidst the deep and profound nonfinite loss and chronic sorrow that their young people may never graduate from high school or university, as they desire, or may never be happy and feel a sense of pride and accomplishment in themselves due to repeated failures.

That is where nonfinite loss bites. It seeps into families waking hours. It seeps into families’ dreams. It seeps into families’ relationships with others, where they too, feel a sense of shame and guilt for being a burden to their own support systems.

Families remain vulnerable and deeply sad and yet, dialectically, strive to remain eternally hopeful, proud and full of admiration for the courage their young people demonstrate, to keep going despite their challenges. “Grief never ends….but it changes. It’s a passage. Not a place to stay. Grief is not a sign of weakness. Not a lack of faith…. It’s the price of love” (Queen Elizabeth the First).

Conclusion

As Neimeyer et al., (2011) suggest, "although nonfinite losses are certainly not new to the human condition, our attention to, and better understanding of loss experiences that have an ongoing presence comprise an important addition to the current bereavement literature (p. 244). In my opinion…more research is needed on nonfinite grief and loss and certainly in relation to how collaborative practice may in fact help alleviate the most severe of the symptoms of this most *natural* trauma response to uncertainty and ongoing ambiguity.

In concluding this chapter on family nonfinite grief and loss, with respect to their young person's chronic mental unwellness, the importance of ongoing self-care in this often arduous journey, is paramount. "The degree to which [we all] can take care of [ourselves] often reflects directly on [our] ability to foster the well-being of [others, including] [our families, and our] clients" (Winokuer, & Harris, 2011, p. 204). Vasquez and Pope (2011) concur, as they too state that, " paying attention to the self is crucial and self-care strategies that support strengthen, deepen, replenish and enliven [are effective]… and can change over time, calling us to create new strategies" (p.77). Further to all of the above, in Chapter Four I will discuss the research, in detail of how families report that the experience of family-led as well as professional-led collaborative approaches to family support groups are an effective self-care strategy that has numerous positive benefits, not only in relieving the symptoms of nonfinite grief and loss in family members, but also concurrently promoting greater functioning of the unwell young person.

Chapter Four

Introduction

The purpose of this chapter is to examine the similarities, differences and effectiveness of peer-led support/education groups and professional-led support/education groups within the context of families with children or youth with mental wellness challenges, highlighting research around collaborative practice. I will briefly outline the core aspects of groups, including the efficacy of groups in general, looking at the overarching purpose and tasks of family support groups. I will examine what types of therapeutic factors emerge in peer and professional-led groups, referencing Yalom's eleven therapeutic factors (2014)

Additionally I will examine how family support groups may not only alleviate the sense of isolation, stigma and nonfinite grief and loss families commonly experience; I will highlight how meaningful collaborative practice within a group setting is showing increased promise of being a best practice example. I will utilize peer- reviewed articles related to research on family-led and professional-led support groups highlighting potential similarities and differences of these groups, while recognizing that "few studies to date have examined whether groups led by professionals provide greater benefits [to families] than do those led by families" (Picket et al.,1998).

What is certain is that families with young people with mental health challenges need support, psycho-education and connection with peers to learn coping strategies, such as those described in Chapter Three, which, as studies demonstrate, reduce or alleviate the trauma responses and symptoms of nonfinite grief and loss.

Lastly, a discussion will follow about the key recommendations of collaborative practice, as defined in the previous chapters, and below, with respect to peer-led and professional–led support groups. In the previous chapters, as well as the discussion below, will demonstrate the importance of more research in this specific area of family support groups, and the need for learning the how of effective collaboration with families within a peer and/or professional-led family support group model.

Before elaborating below, it is important to distinguish that, as Picket et al., (1998) suggest, "there are few significant differences between the [peer and professional-led] groups", in terms of the focus, tasks and therapeutic factors that emerge. What is different is the amount of time spent in group, on specific tasks.

This is critical, as the differences of the groups, as stated above, learned through the limited current research, will highlight the key ingredients that increase effectiveness, in terms of family coping, including ability to manage symptoms on nonfinite grief and loss. Perhaps even broader, future research may examine, in more detail, the positive influence of effective groups on families, which may enhance the sustainability of families as a whole, which as evidenced in Chapter Three, as a result of chronic family stress, due to an unwell young person; families literally crumble. Further, as will be highlighted below, improved family coping as a result of peer/professional-led family support groups have shown to have the added benefit of increased coping of the young person.

Again, Picket's (1998) research findings regarding the differences of group are acknowledged as limited, in that there are few studies in this area to refute or confirm such findings. The underlying principle throughout this chapter is that collaborative practice, from a family-centered perspective, is the approach best suited and necessary to enhance a co-facilitation model of group family support.

Key Definitions Framing My Philosophical Stance:

Before examining the research regarding these two types of family support groups, it is important to provide the definitions of several key terms, as there are numerous models with similar philosophies.

Peer-Led Groups

First, "peer-led groups [in this context]… are when a [family member with a child or youth … with a mental wellness challenge] is facilitating. The aims are similar to professional-led support groups, providing social interaction and peer support" (Diefenbeck et al., 2014), however the underlying premise is that the peer-facilitator is *not* the expert and in fact, each member of the group has their own expertise that they bring to group.

Professional-Led Groups

Professional-led groups, by contrast, "are led by experts who determine what the [family] needs and how to address those needs". Throughout this chapter I will refer to peer-led and professional-led, however it is simply as a way to differentiate between the two facilitators of these groups. Facilitation versus leader is implied, when referring to peer or professional-led.

Professional-Centered Model

Professional-Centered is a model that some professionals still subscribe to whereby "families are seen as deficient in solving their problem and are expected to depend on the professional" (Chou et al., 2014).

Family-Allied and Family-Focused Model

The Family-Allied Model, in contrast to the above, is "where professionals view families as being able to implement interventions, but the needs…[and] the interventions are determined by the professionals. [Further, even the Family Focused Model leaves room for improvement in that it] views families as having the capacity to choose among various options presented to the family by professionals….[yet] families are [still] seen as needing professionals for advice and guidance" (Chou et al., 2015).

Family-Centered Model

Of great emphasis throughout this chapter is the importance of the awareness of and intentional shift towards an authentic family-centered model whereby "professionals view families as equal partners and practices are family-driven; families are the final decision makers; [and] intervention is individualized, flexible and responsive to family-identified needs…"(Chou et al., 2015).

Trauma- Informed Practice

This approach "focuses on safety and engagement. The key principles of this practice are, safety, trust, choice, collaboration and empowerment (TIP Guide, 2013)." Trauma-informed practices view interactions through a lens of identified or possible trauma. This approach is also "family-centered" as defined above.

Collaborative Practice

Collaborative practice, of which this entire thesis is about, and again has been defined in Chapter One, is a complex practice and one in which there is no clearly defined and agreed upon definition. To summarize, ARACY (2009) defines collaborative practice as based on a stance of "producing something new, from the interactions of people and organizations, [via] their [shared] knowledge and resources". A Canadian definition of collaborative practice, Kates et al., (2011), is "care that is delivered by providers from different specialties, disciplines, or sectors working together to offer complementary services and mutual support".

Further, and of key importance to the underlying philosophy of collaborative practice in this chapter, regarding groups, is that "collaborative service delivery [and practice] also extends to the meaningful involvement of families, youth and individuals with lived experience in mental health services" (McDonald, Rosier, 2011).

What is notable to all of the above is that there is "no- clear-cut definition for collaboration." According to Chou et al., (2015), five core principles emerge, when trying to define collaborative practice. These five core principles are: sharing, partnership, interdependency, power and process. [Clearly], there are many dimensions to collaboration. Therein lies the complexity and challenge of meaningful, collaborative practice!

Psycho-Education Groups

Also of paramount importance to this chapter is the distinction, between psycho-educational groups and family education groups. Hatfield (1981) suggests that family interventions have been indiscriminately labeled as psycho-education, irrespective of their roots and orientation. Solomon (1996) states that "family psycho-educational intervention [groups] include both educational and therapeutic components…. typically involving etiology, diagnosis, symptoms…. and treatment of the ill relative….[and that they] were developed to

meet the needs of the ill relative….[Furthermore and of importance], psycho-educational approaches have been traditionally framed… on the predominant conceptual basis …[of] expressed emotion [and] the families attitudinal affect toward the ill relative".

The above distinction is also critical to the underlying philosophy of this chapter, and thesis, as "expressed emotion has been operationally defined as the family's degree of criticism, hostility or rejection and over-involvement, as measured by the Camberwell Family Interview (Solomon, 1996)." Not only do families of mentally unwell young people, take great exception to the concept of expressed emotion, it is now widely accepted in psychology research that "expressed emotion is a [highly] controversial concept, and its measure of validity has been questioned" (Solomon, 1996).

The above references back to the term "refrigerator mother", and a serious issue and barrier to meaningful collaborative practice, which is family blame, shame and stigma, which was examined in Chapter Three, regarding the additional challenge many families face: nonfinite grief and loss. Fortunately shifts in this controversial, as well as unhelpful way of viewing families are taking place, such as in the "children's mental health change effort in 1984, [where the overall goal on the part of the federal government [was to] develop… family organizations… and [examine] research and training… on family support (Friesen et al, 2011)". Clearly, even the governments are becoming aware of the need for a major change in service provider perspective. Again, this speaks to the need for meaningful collaborative practice, within the ethical stance of "not knowing" and focusing on the strengths and resources of all involved.

Family Education Groups

In contrast, "family education [and support in a group setting]… has been designed primarily with the needs of the family in mind [and emphasizes] the competencies, not the deficits of the families and does not assume a medical therapy model in which the presumption of pathology in the family being treated is implicit" (Solomon, 1996). The above, again, is an important theoretical distinction as the above term, "expressed emotion, and its premises can significantly affect the development or lack thereof, of key elements of therapeutic alliance" (Rogers, 1951), including empathy, respect, genuineness and validation. In other words, if the above four elements are not present, family members as individuals, and the group as a whole, will not develop cohesiveness, and will likely be unsustainable. Of importance is the fact that even "family education groups" as defined above are not "family-centered", nor collaborative, as professionals *alone,* design them. In future, through meaningful collaborative practice, and as evidenced in later chapters, co-creation of service design and delivery is paramount to optimal supports and services for families with young people with mental wellness challenges.

Therapeutic Value of Family Support Groups

Before continuing to discuss the research around peer and professional-led family support groups, within the context of a young person's mental wellness, I want to state my belief that support groups for family members do have significant therapeutic value. In fact, recent research points to findings that "despite the fact that it is difficult to evaluate the effectiveness [or therapeutic value] of free-standing self-help [peer-led] groups, given that membership is often anonymous, follow-up is difficult and [often] no records are kept, … systematic studies [do] attest to [their] efficacy… (Yalom, 2014). Based on the above, as well

as my own personal experience, collaboratively co-facilitating family support groups, the underlying assumption is that family support groups are therapeutic in nature.

Rogers and Yalom – What Makes Therapy Work?

With regards to both individual therapy and group, in this case, as mentioned above, Rogers (1951), maintains that the key components for creating and sustaining a therapeutic relationship, whether peer or professional-led, is empathy, respect, genuineness, and validation. Yalom speaks not only, to the components above, but also the eleven core factors, necessary for effective group process, which can only be elicited, developed, and sustained by the strong presence of a solid therapeutic alliance (Rogers, 1951). To be specific, Yalom (2014) states, "the [eleven] therapeutic factors are the *core*…aspects of the experience that are intrinsic to the therapeutic process…and…are universal, overarching, and remarkably similar across groups." Without the above, as is likely the case with a group where "expressed emotion" is the underlying philosophy, there is little hope for therapeutic gains. That is why it is critical that in a group, whether peer or professional-led, (however best when meaningful collaboration between family and professional happens), the theory behind the group must be more than family educational where the professional is viewed as the expert, and be framed from a family-centered lens, and even more so, *not* psycho-educational, where, as defined above, families are viewed as deficit based. All of the above is again critical to effective family support, individual and groups, and again, collaborative practice, with the core ethics behind and framing the practice is key.

Further to the above, and regarding groups, of Yalom's eleven therapeutic factors: universality, instillation of hope, self-understanding, imparting information, family re-

enactment, interpersonal learning, catharsis, altruism, the corrective recapitulation of the primary family group, socializing techniques and imitative behavior, most are required to produce an effective group experience. Some factors, however, such as group cohesiveness, instillation of hope and universality appear to be more effective than others, with regards to family support groups, as identified by families. Family members perceptions about which therapeutic factors are considered more effective are of paramount importance. "Research shows that therapists and [family members] differ in their valuation of group therapeutic factors" (Yalom, 2014). Furthermore, family members and therapists rated certain therapeutic factors higher, at different points throughout group, again highlighting the different lenses through which family members, professionals as well as group's, as a whole, subjectively view therapy.

All of this is important in that authentic, meaningful collaborative practice, which, as research below will highlight, reduces family's trauma and nonfinite grief and loss, as families learn about coping strategies and receive nonjudgmental support, not only from one another, but also from the therapist. Of note, is the key point that different types of groups, whether family support or other group type, and whether peer or professional-led, requires attention to different therapeutic factors. For example, with family support groups, the factors of imparting information, universality, installation of hope, group cohesiveness and altruism are rated consistently high, both by family and professionals.

All of the above, points again to the need for "continued [collaborative and family-centered] research on the mechanisms of action/change of support groups for caregivers" (Diefenbeck et al., 2014). Of significance, is that the specific factors that lead to best practice, for family support groups, as identified by family members, remain largely unknown.

Hatfield agrees and also states "controlled research on family education is limited" (Hatfield, 1981). What is known is that "psychotherapy research will never provide the certainty we crave, and we must learn to live effectively with uncertainty", and yet more work in this area is required.

The message I want to emphasize thus far, highlighted by the above, is that "we must listen to what clients [and family members] tell us…" [about what they need and what helps] (Solomon, 1996). We know we need to be collaborating with families about what works best for them. "Nothing about us without us" is a slogan used by the National Federation of Families in the United States. Researchers and families must work together (collaborate) to "identify family…preferences… by building relationships, compiling evidence and sharing information and skills" (Friesen et al., 2011). The framework to look at collaborative group practice might be in the collaborative research and evaluation and participatory action research models. A discussion of the above types of collaborative research models, is beyond the scope of this thesis, however, again, clearly, further research into collaborative practice, looking at the elements that produce meaningful collaboration, from an individual or group therapy lens, as well as system-wide collaborative lens, the research is lacking at this time.

Group Tasks- How They Differ in Peer-Led versus Professional-Led Groups?

Group tasks refer to the goals of group that lead to its helping and healing capacity. "Groups [in general and family support groups in particular, whether peer or professional-led] provide improved coping, [promote] greater wellness for family members [as well as the unwell young person], [promote] greater knowledge of mental health topics and services available, reduce

the use of other health services, decrease isolation, increase social support, increase advocacy and system change, [as well as] increase problem solving skills (Picket et al, 1998)."

As referenced above, advocacy and system change are two key areas of focus or tasks of family support groups, as identified by family members, and since both advocacy and needed system change have been highlighted in previous chapters as known challenges, when required, contribute in large part to parent/caregiver stress, burden, and ultimately nonfinite grief and loss. Stigma, too, is a key factor for families to overcome. "Family support groups, [whether peer or professional-led] provide a forum to share experiences…..and work to overcome community stigma" (Wintersteen & Young, 1988). Unfortunately, in my experience as a professional working with families, stigma, shaming and blaming are reported far too often. Research shows that "while blaming and stigmatizing attitudes from professionals seem to be waning" (Wintersteen & Rapp, 1987), families still report evidence of "conscious or benign neglect " or being ignored (Zirul & Rapp, 1987).

Understandably, family members are greatly impacted by feelings of stigma and shame and blame. As discussed in Chapter Three, stigma leads to fewer young people and their families seeking supports, and if they do seek out supports, the above feelings can lead to a significant breakdown in the therapeutic alliance in both individual as well as in group settings, which affects the group's functioning, as a whole. As Wintersteen and Young (1988) cite, "the literature graphically describes the sense of distance and isolation from professionals, experienced by many family members (Appleton, 1974, Torrey, 1983; Hatfield, Fierstein, & Johnson, 1982, Lamb, 1982).

As mentioned and evidenced by feedback from family group members, I have been witness to, as well as quotes from families from the *Still Waiting Report* (2013), as per

Chapter Three, families continue to report feeling disrespected, invalidated, feel service providers are disingenuine, and/or lack empathy, regarding their young people.

The above again illustrates the great need for a collaborative practice model, as discussed in the preceding three chapters, which highlights the "the time-tested value of banding together [as per support groups] to cope with …major illnesses", according to Rustad (1984), cited by Wintersteen (1988). In keeping with the above, it is an important piece in peer-led groups; and in particular, that advocacy and stigma remain a key focus. Notable steps forward, by families, banding together in a group, within a collaborative model of family-centered partnership, is the Vancouver Coastal Health Family Advisory Committee (FAC), where a family member sits as the chair. Through this joint venture, with professionals and a health authority, the FAC co-created a plan, which resulted in the successful implementation of the Vancouver Coastal Health Family Support and Involvement Policy (2013).

The intent behind, and hope of the Family Support and Involvement Policy, is to not only help shift professionals, as well as systems towards increased family-centered and collaborative practice, "it is [about] providing a framework for [examining] changes in access, voice and influence… working together toward mutual goals" (Friesen, 2011). This is important for many reasons. Least of all, is that given the benefits of families increased knowledge, coping, and involvement and engagement, in part, through the benefit of collaborative family support groups, as well as other collaborative practice models and examples, as mentioned in previous chapters; families are in a better position to provide helpful support to their young people, and flourish, as a whole.

Further to the above, "given the excessive amount of unpaid services that caregivers [family members] provide that would otherwise further burden our health care system and

society, it is imperative that [professionals and] researchers [co-] develop and [co-evaluate] interventions such as peer-led [support groups] that can [not only] help alleviate the psychological burden of care giving, [they may also] ensure continued family care for the chronically [unwell]" (Diefenbeck, 2014).

Even though the therapeutic value of peer or professional-led family support groups for those with mental wellness challenges "has [according to Wintersteen] been extensively catalogued, [showing improvement in family knowledge] about the illnesses,… treatment; [learning of] effective coping strategies….and [providing families with] the opportunity to express their feelings of fear, anger, [nonfinite loss and] grief,...confusion, and [certainly] the [opportunity to, and] desire to impact service systems…"(Wintersteen, 1988), there is still, according to my literature review, little research on the details of what makes these groups most effective. This stands true and is demonstrated in recent research on family support groups where Wang and Chien (2011) also state "further research is recommended to examine the net and longer-term effects of family support groups in improving knowledge and skills in care giving…which can improve caregiver psychosocial health".

Peer- Led Family Support Groups: What Families Say About Collaboration

Given all of the above factors that contribute to an effective group, whether peer or professional-led, and given the paucity of research in this specific area around the purported benefits of peer over professional-led groups, it is helpful to examine family reported pros and cons. As evidenced above, "self-help groups make extensive use of almost all of the therapeutic factors, especially cohesion, universality, imitative behavior, installation of hope, and catharsis" (Yalom, 2014). In other words, "researchers confirm that many of Yalom's

therapeutic factors were present in a non-professionally facilitated (peer-led) [support group] (Diefenbeck, 2014). There was, however, one notable exception to the therapeutic factors which emerged in group; interpersonal learning, which I will discuss later, however, of the eleven therapeutic factors, the ones that did emerge were, according to Yalom (2014), some of the most effective and beneficial; 'installation of hope, group cohesiveness, catharsis, altruism, and universality." Families agree with Yalom's findings.

Further, "research on the family burden of mental illness [or mental unwellness], has shown that …. psychiatric disorders cause enormous stresses and disruptions in the lives of families" (Solomon, 1996). Collaborative practice, in a group setting, as evidenced, can alleviate some of the stress and disruption. When, as I have personally experienced, via co-facilitating with a family member in a family support group context, peer-instructors are more plausible in offering resources, [and support] than professionals. The experiential know-how of peer facilitators was also rated very high amongst family members, where real-life experiences were shared (Diefenbeck, 2014). "Peer-instructors not only teach participants about basic facts about mental illness and its treatments; they serve as real-life examples of recovery, [and] instill hope…" (Picket et al.,1998). As evidenced in the Chapter Three, maintaining hope is critical for family, in terms of reducing nonfinite grief and loss.

Family members not only report [peer facilitators] as offering real-life examples of hope, they also report experiencing a greater level of empathy [from peer facilitators] that have been there and personally understand the challenges [a family may be facing] (Diefenbeck, 2014). Additionally, families report greater freedom to be open with peer-led facilitators and be more open to "express their dissatisfaction with the mental health system" (Picket et al., 1998). As mentioned above, family's self-identified need for advocacy and

service access information makes the above particularly potent, as families can be honest about their frustrations with the system without fear of service reprisals for critiques. Of note, too, is that family-led groups appear to focus more on adaptive coping tools and emotional support. On the other hand, professional-led groups focus more on knowledge of the illness and treatment and focus more on the mentally unwell young person, who is not present. Despite these differences, they were not seen as significant, and both peer and professional-led groups reported similar outcomes of satisfaction with attention to the above.

What is of note is that Yalom, a well-renowned professional, "suggests that the therapeutic factor of imparting information may or may not be beneficial" (Diefenbeck, 2014). Yet, despite the above, studies have shown that what is unique to support groups is the high degree of frequency of imparting information, and that families do in fact, rate this very high in usefulness. This discrepancy in the stated needs of families, versus professional perceptions, highlights the need for more research, more collaboration, again, where family feedback, as in Participatory Action Research (PAR) or the Collaborative Research and Evaluation Model is utilized to collect meaningful data.

These types of models of collaborative research with families and professionals, regarding the effectiveness of family support groups seems to be an identified missing research piece, and may lead to better service design specific to what families rate as important. The above speaks to the belief that [family member] "support groups emphasize the inherent expertise derived from group members' own lived experiences with members filling dual roles of peer and expert, towards mutual self-help and system change (Diefenbeck, 2014). Collaboratively working alongside professionals seems, in my opinion, to be the best-practice model, as described in more detail below.

Professional- Led, What Are The Differences?

"Despite powerful research evidence on the efficacy of groups…, many [continue to] believe that group therapy is second rate…." According to Yalom, group therapy is as effacious as any mode of individual therapy". Almost all eleven of Yalom's therapeutic factors do emerge in family support groups, whether peer or professional-led, however with one notable exception, interpersonal learning. Some studies have shown that "interpersonal learning… plays a far less important role [in support groups]…."(Yalom, 2014). This is perhaps significant as Yalom cites interpersonal learning as being one of the most important therapeutic factors. With this in mind, is it reason for pause about the potential benefit then, to professional-led combined and in collaboration with peer-led?

Researchers such as Magen and Glajchen (1999) have argued that professional-led is, in fact, preferable due to increased interpersonal learning. Further, Lieberman et al., 2004, [also] argue that "professional-moderated support groups are superior in as much as they promote personal expression of negative emotions at a higher rate than peer-led support groups, which they argue is essential for psychological and (possibly) physical well-being". In other words, it has been suggested that only professional-led groups can "contain and explore strong emotions" and [do not] avoid difficult topics (Diefenbeck, 2014). Lastly another reported benefit of professional-led groups is that family members perceive that greater service access for their children or youth may be obtained, as a closer working relationship with professionals (and the agency) is established in group. Therefore, the question still remains, is one group more effective than the other, or is collaboration the key, and if so, under what conditions?

Peer AND Professional-Led: Collaborative Practice in Family Support Groups

Whether a group is peer or professional-led; for families of children or youth with mental wellness challenges, research shows that the core components of group remain similar. What is different is that "families report that there is a greater sense of empowerment and shared ownership for members of peer-led support groups, as the reciprocal nature in which members both provide and receive support far exceeds the benefits of either alone, as evidenced in the studies by Cole & Eales (1999); Pound (2011); Pound et al., (2007), cited by Tregea & Brown, (2013).

Unlike Yalom's assertion that interpersonal learning is important and a critical component of group process, families do not report interpersonal learning as being their top priority or need. What is of note is that peer-led support groups maintain more of a focus on adaptive coping and devote more time to emotional support. Professional-led, on the other hand, tend to focus more on increasing knowledge of the illness and highlight information sharing and issues related to the ill relative (Picket et al, 1998). The above emphasizes that there are indeed some differences between peer and professional-led groups, however the differences are minimal. What is significant is that research examining the factors that make these groups most effective is lacking.

"Despite the potential for [family support groups to] increase access to peer support and enhance psychological benefits, there is little research defining how peer-led…support groups function most effectively, or what the needs of peer leaders are in developing training and sustaining groups" (Tregea & Brown, 2013). Nor is there much research looking at the

effectiveness of collaborative practice, exploring the unique components of peer and professional-led together, and *how* that combination works most effectively.

The above is of utmost importance as some studies show that "nearly half of all support groups do not have a professional leader" (Diefenbeck, 2014). Other studies show that the percentage of peer-led support groups may be as high as 72% versus only 28%, which are professional- led (Tregea & Brown, 2013). This begs the question, if a large majority of family support groups are peer-led, then research into the specifics of effectiveness, training and their sustainability is of an urgent nature. How can peer-led support groups be improved? What if the specific factors of collaboration between peer and professional-led groups are the key to a greatly improved model of care for family members with children or youth with mental wellness challenges?

I would argue that collaboration *is* the missing key. I would argue that joint ventures, with specific roles, guided and informed by family members feedback and using existing, albeit, limited research into this specific co-facilitated model of family support, is necessary. I would also suggest that the research on collaborative practice, which is widely available, might be applied to this specific population, looking at best practices.

Collaborative Practice Recommendations and Best Practices

To take the recommendation of collaborative practice, whether in group, individual or system wide, a step further, collaborative practice leaders, both professional and family, from within government as well as within not-for profit agencies, must examine the *how,* collectively, in order to ensure authentic and meaningful and ultimately sustainable best practices. Collaborative practice is "one that involves mutual participation of families in

practice and policy making as opposed to a traditional model of disempowerment, invisible knowledge, stigma and discrimination, and power imbalances between clients, [families] and professionals" (Ning, 2010).

Collaborative practice can only evolve into a true partnership "whereby researchers and stakeholders collaborate in the design and all phases… of the research process [and ensuing practice, such as a co-facilitated family support group] (Chou et al., 2015). There are many unanswered questions and it seems clear that it is time to translate "the [limited] positive findings from the clinical research into family-driven practice. A critical distinction is that "collaborative [practice and] research *with* families differs from traditional research *about* families"(Chou et al., 2015). Furthermore, in order to learn more about peer and professional collaboration in a group setting, it must be done "from beginning to end, where shared decision making occurs in every aspect of the research study", if the process is examined (Chou et al., 2015).

There is hope, as well as evidence that authentic, meaningful collaborative practice and research is taking place more often and further recent collaborative practice examples will be highlighted in Chapter Five, the concluding chapter of this thesis.

Concluding Thoughts about Collaborative Practice in Group Settings

Despite the fact that family support groups appear vastly different on the surface content level [they] "rely on identical mechanisms of change…" (Diefenbeck, 2014). Universality, instillation of hope, imparting of knowledge as well as advocacy and system change are the primary therapeutic factors as identified by family members. Both peer and professional-led groups seem to be effective approaches to decrease stigma, and the symptoms

of nonfinite grief and loss, while increase coping strategies and improve service design and delivery by building collaborative working relationships with families and agencies. Collaboration, however, is not as easy as it may appear. Stigma, lack of resources, lack of interest, from both sides, as well as patient confidentiality concerns are just a few such challenges to authentic, meaningful collaboration.

Lack of research in this specific area of collaborative practice is surprising considering the sheer number of peer-led groups, and is also a barrier to learning more about collaborative partnership models in group. Also of significance to effective collaboration is the missing element of the *how* of collaborative practice. Further, "it is widely assumed that professional-caregiver collaboration is beneficial and should be encouraged but little is known about the extent to which collaborative relationships are being implemented within mental health systems…." (Andrew, et al., 2009).

Moreover, with collaborative research and evaluation strategies, producing family-centered outcomes, the data may help answer the key questions of what factors lead to the most effective collaborative family supports groups, and consequently may lead to improved supports, knowledge, service design and delivery for family members and their children or youth. In conclusion, not only is family-centered, meaningful collaborative practice identified as the key to providing the most effective and supportive family support, individually, in groups, as well as system-wide; the *how* and the *process* of collaboration are critical.

Chapter Five

The Conclusion

Evidence of Hope: Meaningful/Authentic Collaborative Practice Examples in British Columbia. More Research Needed!

This final chapter will summarize what meaningful collaborative practice is in relation to child, youth and family mental wellness, reviewing the *how* and the *why*, highlighting once again, the critical importance of, and attention to the ethics or "stance" of authentic collaboration. Further, I will showcase recent practice examples of meaningful collaborative initiatives, in British Columbia and look at policies, recommendations, and research-based strategies that contribute to how individuals and systems remain accountable, compassionate, aware and attending to social justice issues.

I do believe there is hope for change and as Dr. Steve Matthias states in his presentation to the B.C. Select Standing Committee on Child and Youth Mental Health in Victoria, B.C., on June 24, 2015:

> I really believe that we can build the best system in the world….[and] we have so much already on the ground, but it's just not integrated,…[nor are we] working with eachother. I don't think it would take a lot of investment to make a real difference and to get youth [and their families] in this province knowing where to go when they need help".

As the above demonstrates, there is an urgent need for collaboration, and Dr. Mathias offers hope , as he believes this integration and collaboration can be done. Of great significance, however, is that:

> Without reform of mental health services to children and youth in British Columbia, we will face increased costs to our health care system, increased interactions between youth and law enforcement, more difficulties in the classroom, and we all have an idea of what needs to be done…..[which is] to integrate, coordinate and collaborate to make the availability of services better known and more effective to meet the needs of children, youth and their caregivers (BCSSC, 2016, p. 12).

Again, what will be the challenge is the *how*….and according to the above mentioned report, it is stated that "to provide more consistent cross-coordination/ collaboration/ integration, broader implementation of integration models is being explored, information is being improved, transition protocols are being developed, and increased involvement is being provided through more Parents in Residence positions and increased family-centered practices" [will be a major focus] (BCSSS, 2016, p.6). Not only is there a need for collaborative practice within child and youth wellness in B.C., there is a desire, a reason, and certainly, now, a clear commitment.

The question still remains, is there the ability to enact meaningful collaboration? This question may soon be answered as participatory action research and evaluation is currently underway, embedded within several collaborative initiatives, such as the Provincial Child and

Youth Mental Health and Substance Use Collaborative, and the B.C. Children's Hospital Trauma Informed Practice Collaborative Steering Committee.

The Why Of Collaborative Practice in Child, Youth and Family Wellness

As highlighted above, not only is it clear that we must work collaboratively and integrate existing supports, while also co-creating new and better youth and family friendly services, it was highlighted in Chapter Two, that collaborative practice is all about the ethics or stance, or lens through which we view ourselves, and others. As service providers, even though we, collectively, have professional bodies with codes of conduct, which offer "aspirational goals, [these are simply goals] rather than… enforceable standards of conduct" (Everett, et Al, p. 18) (Kakkad, 2005, p. 296). Collaborative practice and the ethics behind the model are *not* enforceable standards of practice and, to be clear, are *not* what this thesis is about.

What this thesis *is* about is the above mentioned aspirational goals, which we must all strive for, and *are* the substance of authentic, meaningful collaborative practice and thus the ethics are inextricably entwined. As Vikki Reynolds states, "the practice reveals the ethics" (2012). In other words, collaborative practice is a relational-based philosophy of life, whereby we embrace values over tools or techniques. The above applies to individual practitioners as well as systems at large

Moreover, collaborative practice and the philosophy behind it, is at the root of what individual service providers, families and government, as evidenced from quotes throughout this thesis, are realizing is required in order to shift and reform child and youth and family wellness. We know that collaborative practice "challenges institutional traditions such as

boundaries and, self-disclosure [or even self-awareness of one's biases and belief system which] is critical to proper and successful [engagement]", whether individually or systemically (Anderson, 1997, p. 53).

As outlined in all previous chapters, to be able to offer authentic, meaningful collaboration, this practice requires that individuals and systems fully embrace and in fact, live by the values and ethics congruent with collaboration, whereby people engage inter-relationally, versus intra-psychically, to walk alongside the person(s) or organizations that they work with, in an "as if" stance of possibilities and new ways of viewing a situation (Tomm, 1987). As a matter of fact, the Government of British Columbia now states that "with respect to services for child and youth, the objective should be a collaborative, multi-disciplinary, integrated approach to providing and enhancing a full spectrum of child and youth mental health services (BCSSC, 2016, p. 26).

Further, ethically speaking, collaborative practice, both individually and systemically, is present and future oriented, which invites a dialogical conversation, exploring and uncovering inner resources, through mutual dialogue. As Jeff Chang (2013) writes, it is a "collaborative conversation, rather than a top-down, expert-to-person(s) endeavor" (p.31). Collaborative practice, as noted in previous chapters, is key to not only young people and family engagement with services and supports, but also, as demonstrated above, key to system-wide transformation, such as the child and youth wellness care system.

The *What* and *Why* and Examples of Collaborative Practice in Child, Youth and Family Wellness

I have walked alongside thousands of families, over the previous seven to eight years, supporting, guiding, advocating and I believe, empowering them by meaningfully engaging from a collaborative stance. What is needed, is not only my opinion, but also the opinion of, and acknowledged by, the *B.C. Select Standing Committee, Final Report*, where it is "urged that …unanimous recommendations [are made] for concrete actions to improve child and youth mental health services and that [these recommendations] be undertaken as a matter of high priority" (BCSSC, 2016, p. 6). Additionally, not only is it of "high priority" to take action, but as is evidenced below, the actions recommended, as per above, must be collaborative and integrative.

Indeed, what the *Final Report* (2016) speaks to is a consistent, person centered, respectful, empathic, strengths-based, safe and trusting approach to child and youth wellness, regardless of where one lives in this province. Further, as we know, "approximately 69% of children and youth with a mental disorder do not receive the specialized, multidisciplinary mental health services they need (BCSSC, 2016, p. 31). This fact has been abundantly evidenced in all previous chapters, and again highlights the urgent need for meaningful collaborative practice. In fact, so revealing is a comment made to me, by a youth, about the lack of all of the above, that I am compelled to write about it, which again highlights the need for collaborative practice, system-wide, and highlights the gap in the system, with regards to accessing consistent, meaningful collaborative practice.

The comment from the youth was made in the context of inquiry into what is collaborative practice. I summarized what I understand it to be, which is all of the above, outlined in this, as well as all previous chapters. The youth immediately said, "well, I sure did *not* experience collaborative practice very often." When asked to expand on her response, she

immediately identified the few people, and organizations, *by name, no less*, who had worked collaboratively with her and how different she *felt* when speaking with them. Moreover, she reported that she continued to access mental health supports, for the first time in her life, due to the shift in *how* services were offered.

Not surprisingly, this young person reported feeling, "listened to, understood, cared about and respected, accepted and honored". These *feelings* this youth is speaking about is what informs and frames the ethics of promoting and engaging in authentic, meaningful collaborative practice, from individual, to group, as well as across systems. Collaborative practice, simply put, is truly about how people *feel,* during and after any *meaningful collaborative* interaction. Collaborative practice is about being with as opposed to "doing to".

Stigma

Further to the above, regarding the need to reform systems through the art of meaningful collaborative practice, it is also framed by the severe need to decrease the stigma, of mental health, as evidenced in all the above chapters, and identified as one of the key reasons why as many as 69% of young people and their families are not accessing services (BCSSC, 2016). "Efforts should be made to decrease stigma so that when mental health issues are identified, children, youth and their families do not feel ashamed or discouraged to seek support" (Evergreen, 2010, p.19). The evidence of the detrimental effects of stigma on families is clear, and has been evidenced throughout this thesis.

Moreover, the intense social stigma of raising a young person with mental wellness challenges continues to create serious distress, trauma and nonfinite loss and grief for significant numbers of families. "Stigma was identified as strongly contributing to a culture of

silence and shame in the school, [and in the community], regarding mental health (Evergreen, 2010, p. 19). As highlighted, collaborative practice, and the ethics behind the practice are supported by, and frame the need to reduce families' shame and blame, which many families weather, often daily. As a youth stated in the Evergreen Framework, "I think the public does not want to believe kids when they tell them something is wrong…like we are just making it up or lying. [Further] this feeling was echoed by a parent …who reported that society still does not want to believe that children have mental health disorders" (Evergreen Framework, 2010, p.19). Stigma that families speak of is truly crippling, and perhaps for some reading this thesis, surprising, that stigma often comes from clinicians, teachers, police, and even from family members.

Further to the need for a reduction in stigma, through meaningful collaborative practice via the ethics, is the push for individual service provider, as well as system-wide attitudinal shifts. This shift can be framed and informed by actively listening to and empathizing with the thousands of families who report feeling the strong sting of judgment, and the resulting isolation, leading to what I describe as oppression and disempowerment, and certainly nonfinite loss and grief.

Simply being present with families is one of the greatest gifts, we, as service providers can offer. The above is certainly true, and, on the other hand, as service providers, it can feel incredibly frustrating to sense that the very system, that we are a part of, and which claims to provide mental wellness supports and services, often does not provide much choice, connection, nor invites, includes or empowers families. As service providers, it is important for us to recognize that we are an important piece of the needed change. Collaboratively, we can work with families, by listening and respecting their expertise. Thankfully, I have

witnessed a shift, albeit at times, small laborious shifts, years in the making, and, by bearing witness to current, meaningful, collaborative practice examples, such as those above and below, "the signs of progress [become more visible and] together we can create an unstoppable movement to improve mental health" (MHCC, p.34, 2012).

Hope By Way of Policies and The First *Ever* Mental Health Strategy for Canada

I do hold great hope, as I am both a witness and participant of numerous current collaborative practice examples, where shifts are taking place in child, youth and family wellness. Some additional collaborative practice examples from across British Columbia and Canada will follow briefly below. It should be noted that meaningful, authentic, collaborative practice examples are not only across British Columbia and Canada, but also throughout Australia, the United Kingdom, and Norway, to name a few. I am witnessing this systemic shift, towards authentic, meaningful collaborative practice, in child, youth and family wellness, with the intentional goal of greater mental wellness for families as a whole.

Nevertheless, I recognize that most service providers, myself included, want to collaborate. I recognize that most service providers are trying their best to collaborate, working within a fragmented and siloed system. I too, recognize that most service providers simply may not know *how* to authentically collaborate, often, inadvertently, we may use language that shames and blames. Regardless, I recognize and believe, too, that the families we are honored to work with may possibly be our greatest teachers, if we are open to learning…and…. if we engage with curiosity and a stance of "not knowing" (Andersen, 1997).

Similarly, when we hold an ethical stance, we may remain hopeful, and engaged, leading to greater learning from each other, both inter-professionally and with families. Due to the fact that I have been privileged to be part of a numerous collaborative, and meaningful practice initiatives across British Columbia, I remain hopeful for this shift. Below are examples of some recent, B.C. based collaborative initiatives, which are effective cross-systems initiatives in the *Healthy Minds, Healthy People Engagement Summary* (2014). One such example, is The F.O.R.C.E. Society for Kid's Mental Health, now the FamilySmart Institute of Families, which has modeled collaborative practice since 2000, and continues to fine tune and offer an ethical presence by reflecting and engaging in active curiosity, with families, as well as government, asking the question of themselves and of others, "How am I showing up?

This question is key, allowing for increased likelihood of practicing authentically and collaboratively, and must be asked by organizations as a whole, as well as individuals. We must reflect daily about our ethical stance or way of being. Moreover, organizations and individuals must continually attend to *not* being "fixed or static, but fluid and living" (Everett, B., MacFarlane, D., Anderson, Reynolds, V., Anderson, 1997, p.18).

In summary, individuals, organizations as well as government must focus keen attention on the creation of new and relevant mandates and policies, reflecting a collaborative stance, allowing shifts to take place, by learning, through doing, and modeling the *how* and the *what* of collaborative practice. "Many health care systems world-wide have acknowledged that mental health care should be consumer-and family-oriented" (Davisdon et al., 2006, EOHSP, 2007) (Lavoie-Tremblay et al., p. e47, 2012). In other words, working collaboratively, with families and consumers is considered best-practice, worldwide.

In order to make meaningful collaborative, happen, individuals, organizations and government must make it part of their mandate, philosophy and vision. Case in point, the F.O.R.C.E. Society's mandate is to "support and empower families and work collaboratively with professionals and systems in understanding and meeting the mental health needs of families" (F.O.R.C.E. Society, 2000).

Another example of a strategy, in action is from the Mental Health Commission of Canada's key *strategy* towards authentic collaborative practice whereby Vancouver Coastal Health's (VCH) Family Advisory Committee (FAC) co-created a Family Support and Involvement Plan (2004), which led to the co-creation and co-implementation of the Family Support and Involvement Policy (FSI), (2013). The FSI Policy has highly influenced a system-wide shift in how VCH engages collaboratively; actively seeking out and empowering families in multiple aspects of service design and delivery. "According to decision makers, family collaboration should be fostered between families and the health care system" (Lavoie-Tremblay et al., p. e47, 2012). Indeed, collaborative practice can shift and reform the mental health and wellness care for young people and their families.

Further Evidence of Collaborative Practice Examples

As additional illustrations, numerous collaborative practice examples now exist in B.C., however most examples have taken place just in the previous two to five years. This again coincides with the policies and plans emerging from the Mental Health Commission of Canada, such as the above mentioned *Strategy* from 2012, as well as the earlier document, *The Evergreen Project* (2008), resulting in the *Evergreen Framework (2010),* which also,

> Prioritized the active involvement of people from across Canada in all aspects of creating a framework specific [for] child and youth mental health. [Importantly] in this spirit of collaboration young people, parents, educators, mental health professionals, and countless others

> involved in the lives of young people, came together using online technologies to build Evergreen from the ground up (MHCC, 2010).

Again, these recent examples of collaborative practice, system-wide, are critical and needed, and now, happening. The question remains, how do we measure if these initiatives are engaging in meaningful and authentic collaborative practice, with attention to power imbalances, and the process, as well as ethics and stance of "not knowing"? This important question remains to be answered from a research perspective, and is one area that further research and study is needed.

Notwithstanding the lack of available research into what is the exact nature of meaningful, yet another current example of collaborative practice in B.C. is the *Youth Mental Health Transition Protocol Agreement,* between the Ministry of Family Development (MCFD) and Ministry of Health and Health Authorities (MOH, MOHA), which was created June 11, 2015. This protocol agreement states "MCFD and the MOH, through the health authorities [will] facilitate a collaborative approach to transitioning youth/young adults from Child and Youth Health Services to Adult Mental Health and Substance Use Services" (2015). The above again highlights a significant transformational shift in systems and services, whereby ministries, perhaps for the first time ever, are collaborating to achieve increased access to much needed youth and family supports.

Consequently, the above collaborative protocol agreement is the result of an identified gap in transition planning, emphasized and documented by another recent collaborative practice initiative between a family-led not-for profit agency, The F.O.R.C.E. Society, and the Representative for Children and Youth, (RCY). This critical transition age gap features prominently as a key systems issue in the *Still Waiting Report* from 2013, regarding child and

youth mental health in British Columbia. The RCY Report highlights the severe lack of collaboration, as one of the main issues in youth mental health care.

As a matter of fact, in 2013, just three years ago, most of the above and below collaborative practice examples were simply not happening and youth and families were left hanging, often, sadly, quite literally. "Suicide is the number one cause of non-accidental death among youth" (Right By You, 2012). Thankfully, "young people, parents and families are exercising their rights by becoming active participants in all aspects of child and youth mental health (Evergreen Framework, 2010, p. 11).

Another very recent collaborative practice example is the B.C. Integrated Youth Services Initiative (BCIYSI) which:

> Was developed through a collaborative process involving a committed working group….[and] was informed by regular consultation with a Governing Council, comprised of senior representatives from the three funding organizations, as well as the BC Ministry of Children and Family Development (MCFD) and the Michael Smith Foundation for Health Research (MSFHR)…..[as well as] the Office of the Chief Medical Officer (CMO) for the First Nations Health Authority (FNHA)" (BCIYSI, 2015).

The above example is also of great significance in highlighting how systems are in fact shifting, through collaboration within and across systems and recognizing the need for, and importance of family engagement. Additionally, the above BCIYSI is a direct result of the recommendations from the previously mentioned "Interim Report from the [B.C. Select Standing Committee] (SSC) [titled]: *Youth Mental Health in British Columbia* (2014), documenting best practice examples in BC, such as integrated service delivery, youth-appropriate services, telephone and online counselling, and peer support" (SCC, 2014).

The Interim Report noted "the effectiveness of international models of integrated care…." and further to the above initiative, in June 2016, in collaboration with many partners, including families' voices via the FamilySmart Institute of Families, the BCIYSI undertook a comprehensive evidence-based process, choosing five additional provincial communities (outside of the lower mainland), to work together to create integrated youth health centres and expand the BCIYSI youth initiative across the province. As evidenced, "the BC-IYSI is committed to working with youth, families, and community organizations, as well as government officials to meet [their] stated objectives [which] include:

> A comprehensive system of care ensur[ing] that health promotion, prevention and early intervention are core components, services be timely, accessible, developmentally appropriate, socially inclusive and equitable, and culturally sensitive, congruent, and safe, services are youth-and family-centered, collaborative and empowering to both, [and the] integration of services…. occur through intentional partnerships and collaborative inter-sectorial working relationships, with special attention on the actual process of integration. (www.bciysi.ca)

Again, the BCIYSI is yet another recent collaborative best practice example of the needed critical shift in how health authorities and service providers can collaborate in a meaningful way, and work together, with young people and their families, towards effective change for everyone, all across British Columbia.

Further examples from the *Healthy Minds, Healthy People Engagement Summary,* 2014, of "effective cross-system initiatives in British Columbia" are:

> The Community Action Initiative, SACY (School Age Children and Youth), …, First Nations Health Authority, *A Path Forward*, Health and Education Work around School Connectedness [such as the BCMHSUS Summer Institute], Trauma Informed Practice Guidelines, MCFD FRIENDS Program, School Centred Mental Health Coalition, Take Home Naloxone, [involving] public health, law enforcement and professional bodies, ….Interior Health Collaborative, [and] the LINK Project (Vancouver), [involving] public health and police. (p. 21)

As the BC Select Standing Committee's *Final Report*, *Concrete Actions for Systemic Change* (2016) states, "children, youth and young adults are suffering as a result of significant weaknesses and gaps in services, [which is why] the committees second core recommendation is for an integrated [and collaborative] service delivery model (p.6). Clearly, as evidenced in all previous chapters, collaborative practice is not only needed; it is critical to shifting policy and practice, whereby young people and families, as a whole are supported and may flourish.

By way of explanation about the above *Final Report* (2016), as well as the *Summary Report (2014)* "this [2014] report outlines the results of a [collaborative] public engagement process hosted by the [Minister of Health] MOH and [Minister of Children and Family Development] MOCFD to gather input into the second three years of *Healthy Minds, Healthy People: A 10 Year Plan, to Address Mental Health and Substance Use in British Columbia, released in November 2010" (2014).* Of importance to the above *Plan* (2010) and the *Summary Report* (2014) is that both reflect an ongoing collaborative effort, which resulted in the B.C. government utilizing a similar collaborative process in 2013, 2014, and 2016, with the intent and commitment to addressing recommendations, of which the earlier *Plan* (2010) recommended the need for a mental health strategy, which previously, did not exist. Consequently, in 2012, for the *first* time in Canada, a *Mental Health Strategy* was released.

> *Changing Directions, Changing Lives Strategy (2012)* is the culmination of many years of hard work and advocacy by people across the country. A key driver behind its development has been the testimony of thousands of people living with mental health problems and illnesses, [and their families]. In increasing numbers they have found the courage to speak publicly about their personal experiences and the many obstacles they face in obtaining the help and support they need from an underfunded and fragmented mental health system. Family members have echoed this assessment while pointing to the many challenges that they also confront (MHCC, p. 1, 2012).

As mentioned above, this *Strategy* is the *first* mental health strategy, *ever*, for Canada. "Its release marks a significant milestone in the journey to bring mental health 'out of the shadows' and to recognize, in both words and deeds, the truth of the saying that there can be "no health without mental health" (MHCC, p. 2, 2012).

In conclusion, I cannot emphasize enough the deep significance of the Canadian Mental Heath Strategy document, not only for its contents which highlight vital key strategies, including the need for authentic collaboration, resulting in hope for improved service delivery and design of mental wellness supports and services for young people across B.C., but also, and perhaps even more importantly, is the process of how this *Strategy* was "developed, [collaboratively] by the Mental Health Commission [of Canada], in close consultation with people living with mental health problems and illnesses, families, stakeholder organizations, governments, and experts, [all coming together around a common goal of] improving mental health outcomes for all Canadians" (MHCC, p. 3, 2012).

As the MHCC states, "this *Strategy* is [seen as] a blueprint for change", and reflects a strategy for all of Canada. Additionally, and of key importance, this *Strategy* also addresses the very serious issue of stigma, which, as evidenced in previous chapters, directly results in families not reaching out for needed help and support. The *Changing Directions, Changing Lives Strategy* (2014) states that stigma will be addressed by "….raising the profile of mental health issues and encouraging public discussion of [stigma] to reduce [it] in the minds of many, and further [result in] the elimination of the discrimination that feeds on this stigma. Again, all of the above provides me with great hope for a collaborative approach to shifting systems, and learning from one another. Further, the raising of the profile about child and youth mental health was in fact achieved in a significant way, on Saturday, October 1st, 2016,

when the Duke and Duchess of Cambridge discussed this very issue with representatives from BC Children's Hospital Kelty Mental Health Resource Centre, in Victoria, BC.

As all of the above and previous chapters describe and highlight, it is clear that a blueprint was and is needed in child, youth and family wellness. In fact, as per a well-known substance use recovery phrase, which states so succinctly, "a goal without a plan is just a wish" (Antoine de Saint-Exupery, The Orchard, 2014). So at last, in 2012, Canada finally has a plan, in fact, a collaborative plan; a strategy, and therefore all of the above is more than just a wish" it provides a plan, resulting in hope for "improv[ing] mental health outcomes for all Canadians" (MHCC, 2014).

One final point, perhaps not required, however added for emphasis for the argument for the urgent need for collaborative practice and resulting research around child, youth and family wellness, the MHCC's *Strategy* document (2014), clearly identifies six key strategies, which are:

> *To promote mental health across the lifespan, …foster recovery and well-being for people of all ages living with mental health problems and illnesses, …provide access to the right combination of services, treatments and supports, when and where people need them, reduce disparities in risk factors and access to mental health services, and strengthen the response to the needs of diverse communities and Northerners…, work with First Nations, Inuit, and Métis to address their mental health needs, acknowledging their distinct circumstances, rights and cultures, healing from intergenerational trauma,….* ***[and lastly, and of extreme significance to this thesis is] to mobilize leadership, improve knowledge, and foster collaboration at all levels***.

Moreover**,**

> ***Change will not be possible without a whole-of-government approach to mental health policy, without fostering the leadership roles of people living with mental health problems and illnesses, and their families, and without building strong infrastructure to support data***

> ***collection, research, and human resource development*** (MHCC, p.4, 2012).

As evidenced in all of the above, the shift towards meaningful collaborative practice is starting to happen, and illustrative of this critical shift in collaborative practice, systemically speaking; due, in large part to the *Changing Directions, Changing Lives Strategy, (2012),* many collaborative projects, committees and advisory boards have been initiated, and demonstrates that collective "passions bind [and] titles ….[are beginning to] *not* confine" (Schulz, Copeland, 2106).

In summary, as mentioned, I am fortunate to bear witness to system shifts and it began with the authentic acknowledgement from the Representative for Child and Youth (RCY), Mary-Ellen Turpel-Lafond that "mistakes have been made" (*Still Waiting, 2013).*

The Importance of "Social Justice" Being Named

Before describing further recent, B.C. based examples of collaborative practice, it is critical to highlight that authentic collaborative practice speaks to advocacy and social justice. As evidenced, the child and youth wellness system is flawed and families are suffering. This is a social justice issue for all, and as Dean Spade states, "social justice trickles up" (Spade, 2012). I firmly believe this and thankfully have witnessed this "trickling up". The *Evergreen Project* (*2010)* is just one example of trickle up, where a project leads to a framework, and ultimately a first of its kind *Mental Health Strategy* for Canada.

Barriers and Challenges to Collaboration- Let's be Honest

Further to all of the above about the ethics of collaborative practice, it would be an omission to not touch briefly on the spectrum of patient and family engagement, [whereby

authentic collaboration moves from] inform, consult, involve; [to a higher level of engagement where] collaborat[ion] and empower[ment]" take place (B.C. Provincial Patients as Partners, p. 11, 2015). Currently, such barriers to authentic collaborative practice are common, as often within the spectrum of engagement, collaboration and empowerment are far less frequently taking place. More often collaboration happens from an inform, consult or involve lens, which, in my opinion, is a start, yet, to be clear, it is *not* authentic collaboration. Much work and on going shared training, as mentioned in Chapter Three, is required for all parties to feel competent and authentic collaborators.

Additionally "there are legal barriers to information sharing by professionals caring for [young people]…[and] some family members also felt that legal barriers, or at least the perception of legal barriers, prevent families from being adequately involved in treatment, particularly of adolescents. [Recommendations around] an integrated system of 'one file, one child"…[as mentioned in the BCSSC Final Report, 2016, p. 30). Similarly, barriers to integration occur as siloed systems of care and "turf protection by professionals in the system", are common (BCSSC, 2016, p.19). Despite what Dr. Steve Mathias stated in presentation on June 24, 2014, where he states, *" I don't think it would take a lot of investment to make a real difference"*, I believe there is, in fact, a *significant amount of* investment that needs to take place to ensure that authentic, meaningful collaboration continues!

Despite, in my opinion, the significant investment needed in order to create a meaningful collaborative practice shift, systemically speaking, I believe in the work currently taking place, in the collaborative initiatives mentioned in the preceding chapters.

The above speaks to how collaborative practice can greatly reduce, and potentially alleviate symptoms of nonfinite loss and grief that so many families experience. It is my belief

that meaningful collaborative practice may, as demonstrated throughout this thesis, result in greater wellness for families as a whole, due to people's sense of increased empowerment, through helping others, via collaborative and co-facilitated family support groups, as just one example, and through witnessing improvements that they themselves have helped shape and inform.

Additionally, and of extreme importance, offering great hope for ensuring the future of collaborative practice in B.C., is the number one key, core recommendation made by the BCSSC (2016), which is to create a new position in cabinet, a "Minister of Mental Health", (in addition to the second core recommendation, previously mentioned above, of collaborative and integrative approaches, at all levels of supports and services for young people with mental wellness challenges, including their families). Therefore, first and foremost, we shall watch and see, what recommendations [are being made] to cabinet by June 30, 2016 on potential improvements (BCSSC, 2016, p.7).

I wonder *when* the public will be informed of the latest recommendations, and *when* the new Minister of Mental Health will commence, and *who* will be appointed to be Minister of Mental Health (MOMH), all the while recognizing that the MOMH's "explicit mandate [will be] to direct funding towards those initiatives that have a collaborative, multi-disciplinary, and branded integrated approach" (p. 27). All of the above and more are extremely important to the formal birth of needed coordinated, integrative and hopefully meaningful *collaborative* practice, all across British Columbia. The time is now!

Speaking further to the best practice collaborative examples highlighted above, all appear to exemplify a stance of collective solidarity (Reynolds, 2012). On the other hand, to be clear, it is critical to remain aware, within these collaborations, collectively, that power

imbalances continue to be a known barrier to authentic collaboration. Despite this known barrier, the above practice examples are extremely encouraging, albeit a constant work in progress.

Not only is recognition of the inherent hierarchy and power dynamics key, the naming of the power imbalance must continue to be a part of the ongoing dialogue, even though it may be uncomfortable, especially as those *with* power, typically experience power as invisible (Walters, 2016). Moreover, those without power are keenly aware of its presence, and it is those individuals who lack power who must do the naming, no matter how difficult. We must remember "the role of [service provider] holds power ranging from superficial to profound, from fleeting to enduring" (Pope &Vasquez, 2011, p.35). Attention, transparency and naming the above are key to authentic and meaningful collaborative practice, especially so in government.

Collaborative Practice: It's Evident That It Is Not So Easy!

As stated in the key findings by Jivanjee & Robinson (2007), collaborative practice is not so easy.

> The complexity of issues [related to collaborative practice, especially between service providers and family members highlights] the need to articulate the intent of the mandate [of the collaboration]. [As mentioned above, in relation to the "spectrum of engagement", […the extent and nature of involvement] must be clear. Next, it is important for training to be made available to [service providers] and family members….as professional training ha[s] not prepared them to work with family members; [and] likewise, most family members report that they ha[ve] no previous formal [collaborative practice] training…and [in fact] joint training sessions [were recommended]….Finally, …there is still a need to establish an evidence base regarding family involvement…. (p. 379-380).

As a further collaborative practice example such as the Provincial Child and Youth Mental Health and Substance Use Collaborative (CYMHSUC) demonstrates, its strong collaborative ethic, is reflected in its very title and charter. The charter states., there is a need for collaboration across sectors, outlining the purpose as being "a powerful change engine to engage children, youth and their families, Aboriginal peoples, [diverse and gender-diverse peoples], physicians, clinicians, provincial ministries, health authorities, schools, and communities…" (Collaborative Charter, Sept. 2014- June 2015, p. 7). The collaborative continues to walk the walk, and engage ethically from a collaborative stance.

Again, the common theme of recent collaborative practice initiatives, including the above example, is the need for systemic change to meet the needs of all young people and their families. By way of further example, the values housed in the collaborative charter are "engagement, valuing emerging evidence-informed approaches from families and youth lived experiences, connection and integration from an interdisciplinary perspective, honoring culturally [and gender] diverse peoples, focusing on strengths and possibilities and promoting a blame- free environment" (Collaborative Charter, 2014, 2015, p.7).

Additionally, promoting a blame-free environment is critically important to meaningful collaboration, and reflects the challenges that young people and families consistently and emphatically reported, as evidenced in Chapters Three and Four. That is, families suffer often from nonfinite loss and grief, in part due to blame and shame and stigma around youth mental health issues, and how through authentic collaborative co-facilitation of family support groups, the feelings of blame, shame and stigma can be reduced. Therefore, the above Collaborative Charter (2014, 2015) highlights once again, a significant shift in practice where a melding of diverse needs and an honoring of the differences takes place.

Also of significance in authentic collaborative practice, the Provincial Child and Youth Mental Health and Substance Use Collaborative Charter "engage family networks from the very beginning" (2014, 2015). This is also critical to authentic collaborative process, whereby this practice seeks out to collaborate and empower all parties, from the start, versus inform or consult with some of those involved, only after the fact. The above again, offers another example of when collaborative practice may *not* be authentic, despite earnest intent.

Conclusion, Moving Forward

In summary, all of the above speaks to the need to collaborate, across disciplines, with families and youth. The above also highlights how "dramatic, [the] rise of family member and youth influence [is] in the field of children's mental health over the last twenty-five years, [let alone in the last five years, and it is important to examine] how increased [collaboration with] family and youth voice has stimulated changes in practice, service infrastructure, and policy to achieve a more family-driven and youth-guided system of care" (Friesen et al., 2011, p. 1).

Also of great significance, and enough importance to re-emphasize, in concluding this thesis; in order to remain authentically, ethically "collaborative", we must remind ourselves of our own "power" and actively practice mindful awareness. To remain within a truly non-hierarchal "stance" of "not knowing, where [we] co-create what is discussed, how it is discussed and what, if anything we might do differently, remaining open and curious, and where we are "invited into a mutual or shared inquiry about the issues at hand" (Anderson, 1997, p. 47).

A brief, however important point, before concluding this chapter, is that to be "collaborative" and open and curious, is not to suggest that we remain passive, and in fact,

quite the opposite is true, where we must remain actively engaged and alert. The above speaks to the collaborative nature of eliciting strengths, utilizing active communication skills, and working together to identify gaps to enhance movement towards a self- identified goal. Again, being collaborative involves the engagement of curiosity, unconditional positive regard and openness, which are key attributes and central to a "not knowing" attitude. If we are "doing" meaningful collaborative practice, which reflects the ethics of "being" person centered and utilizing honoring language, we must do so in all areas of our lives, to the best of our ability. Finally, and of again of importance, is that knowledge and awareness of "our vulnerabilities create[s] a responsibility to question our own views, whether [that be] snap judgments or long-held beliefs" (Pope, Vasquez, 2011, p.18). In other words, collaborative practice is always a "work in progress".

In conclusion, the best way to summarize the ethics of meaningful collaborative practice in child and youth and family wellness in British Columbia is described by Kinman (2009) who states, "like a rhizome, the six guiding intentions [of collaborative practice] grow into and out of each other [and helps] to identify the main threads of an ethical stance." These guiding intentions are, " centering ethics, doing solidarity, fostering collaborative sustainability, addressing power, critically engaging with language and structuring safety" (Reynolds, 2012). If we all collectively practice the above six guiding intentions, then I do believe, as Dr. Steve Matthias states, *"we can build the best* [and most meaningful collaborative child, youth and family wellness] *system*, [not only within British Columbia, but also] *in the world*".

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