

Manufacturing marginalization: Parenting services from the perspective of  
parents with mental illness

by  
Ginna Abramovitch  
B.A., Carleton University, 2001

A Thesis Submitted in Partial Fulfillment  
of the Requirements for the Degree of

MASTER OF ARTS

in the School of Child and Youth Care

© Ginna Abramovitch, 2015  
University of Victoria

All rights reserved. This thesis may not be reproduced in whole or in part, by photocopy or other  
means, without the permission of the author.

**Supervisory Committee**

Experiences of parents with mental illness of parenting services: A pilot study

by

Ginna Abramovitch  
B.A., Carleton University, 2001

**Supervisory Committee**

Jessica Ball, PhD, Supervisor  
(School of Child and Youth Care)

Gordon Miller, PhD, Departmental Member  
(School of Child and Youth Care)

## Abstract

### Supervisory Committee

Jessica Ball, PhD, Supervisor  
(School of Child and Youth Care)

Gordon Miller, PhD, Departmental Member  
(School of Child and Youth Care)

This exploratory study begins to fill in a large gap in the understanding of how parents with MI access parenting services and how they perceive this process. Constructivist grounded theory by K. Charmaz (2006) was the guiding methodology. The findings point to the strong influence of the service context on the process and outcome of parental engagement with services. Parents identified a fragmented, restrictive and reactive context of parenting services that failed to support them and their families. They described a stigmatizing and disempowering service response. The parents' process of service engagement paralleled a process of marginalization they experienced in society. Government and community services were distinguished by degrees of restriction and approaches to practice. Community services were most commonly viewed as supporting parents and working as allies. The findings underscore the importance of engaging parents with MI as partners in research and development of service policy and practice.

## Table of Contents

<b>Supervisory Committee:</b> -----	<b>ii</b>
<b>Abstract:</b> -----	<b>iii</b>
<b>Table of Contents:</b> -----	<b>iv</b>
<b>List of Figures:</b> -----	<b>viii</b>
<b>Acknowledgments:</b> -----	<b>ix</b>
<b>Chapter I: Factors of service use by parents with mental illness:</b> -----	<b>1</b>
Introduction:-----	1
Individual and family level factors:-----	3
<i>Demographic factors:</i> -----	3
<i>Parental illness factors:</i> -----	3
<i>Child factors:</i> -----	4
<i>Family factors:</i> -----	5
<i>Social supports:</i> -----	5
<i>Cultural factors:</i> -----	6
Service context factors:-----	7
<i>Assessment and intervention factors:</i> -----	8
<i>Service access factors:</i> -----	9
<i>Service provider factors:</i> -----	11
<i>Discrimination of the mentally ill and associated factors:</i> -----	12
<i>System-level factors:</i> -----	13
Conclusion:-----	14
<b>Chapter II: Guiding Methodology:</b> -----	<b>16</b>
Methodology:-----	16
<i>Gathering data:</i> -----	17
<i>Analysis:</i> -----	17
<i>Coding:</i> -----	18
<i>Memo-writing and analytic aids:</i> -----	20
<i>Theoretical sampling and saturation:</i> -----	20
<i>Evaluating CGT:</i> -----	21
<i>Summary:</i> -----	22
Limitations:-----	23
<b>Chapter III: Methodological considerations:</b> -----	<b>24</b>
Recruiting participants:-----	24
<i>Theoretical sampling and sample size:</i> -----	25
Gathering data: -----	26
<i>Constructing focus groups:</i> -----	26
<i>Constructing in-depth interviews:</i> -----	29
<i>Observing and recording in field notes:</i> -----	31

<i>Applying reflexivity:</i>	31
Conclusion:	32
<b>Chapter IV: Method:</b>	<b>33</b>
Recruitment:-	33
<i>Participant criteria:</i>	33
Initial selection:-	35
<i>Sample size:</i>	37
<i>Theoretical sampling:</i>	38
<i>Screening:</i>	38
<i>Ongoing screening:</i>	39
<i>Consent to participate:</i>	40
<i>Ongoing consent:</i>	43
Data gathering:-	43
<i>Focus groups:</i>	44
<i>Composition:</i>	45
<i>Process:</i>	46
<i>Summary:</i>	49
<i>Individual interviews:</i>	50
<i>Observations:</i>	51
<i>Member-checking:</i>	53
Limitations:-	53
<b>Chapter V: Process of Analysis:</b>	<b>55</b>
Coding:-	55
Memo-writing and diagramming:-	57
Language:-	58
<b>Chapter VI: Findings:</b>	<b>59</b>
Introduction:-	59
Engaging with parenting services:-	61
<i>The parenting services context:</i>	61
<i>Falling through “The Gap”:</i>	61
<i>Experiencing “The System”:</i>	64
<i>Getting through the gate:</i>	65
<i>Being granted access:</i>	66
<i>Enduring the process:</i>	66
<i>Seeing the big picture:</i>	69
<i>Responding — Not giving up:</i>	72
Supporting parents:-	75
<i>Supportive context:</i>	75
<i>Supportive processes:</i>	77
Tearing down walls - Building bridges:-	79

Summary of recommendations:	82
Disseminating findings:	83
Intent for findings:	85
<b>Chapter VI: Discussion:</b>	<b>86</b>
Introduction:	86
Sketching the context of parenting services:	88
<i>The context of parenting services for parents with MI:</i>	88
Community:	88
Systems:	89
<i>Fragmented, restrictive, reactive service response:</i>	93
<i>A fragmented spectrum:</i>	93
<i>Restrictive access and inadequate response:</i>	94
<i>Cyclical, crisis-driven pattern of access and response:</i>	96
<i>Conclusion:</i>	96
Experiencing “the system” of parenting services:	97
<i>Parallel processes of manufacturing marginalization:</i>	97
<i>Stigmatizing:</i>	98
<i>Systemically discriminating:</i>	98
<i>Silencing:</i>	99
<i>A gendered lens on manufacturing marginalization:</i>	101
<i>Resistance and resilience — “You can’t give up!”</i>	104
<i>Conclusion:</i>	105
From problems to solutions:	106
<i>A change in perspective — the social justice approach (SJA):</i>	107
<i>SJA and prevention:</i>	109
<i>Poverty reduction as prevention:</i>	110
<i>Stigma-reduction as prevention:</i>	110
<i>Where’s the evidence?</i>	111
<i>Recovery-based services within the prevention framework:</i>	112
<i>From collaboration to accountability:</i>	115
<i>Working as allies to achieve change:</i>	116
Conclusion:	118
<b>References:</b>	<b>122</b>
<b>Appendices:</b>	<b>151</b>
Appendix A: Recruitment Poster	151
Appendix B: Invitation Letter	153
Appendix C: Initial Screening Script	154
Appendix D: Initial Screening Questionnaire	160
Appendix E: Participant Consent Form	162

Appendix F: Consent Discussion Script -----	173
Appendix G: Release of Identity Consent Form -----	181
Appendix H: Ongoing Screening and Consent Form-----	183
Appendix I: Phase II Individual Interview Questions-----	185
Example 1:-----	185
<i>Example 2:</i> -----	187
Appendix J: Initial Coding-----	189
<i>Example 1:</i> -----	189
<i>Example 2:</i> -----	190
<i>Example 3:</i> -----	191
Appendix K: Focused Coding-----	192
<i>Example 1:</i> -----	192
<i>Example 2:</i> -----	193
Appendix L: Memo-writing -----	194
<i>Example 1 (early stage):</i> -----	194
<i>Example 2 (early stage):</i> -----	195
<i>Example 3 (early stage):</i> -----	197
<i>Example 4 (reflexive):</i> -----	198
<i>Example 5 (reflexive):</i> -----	199
<i>Example 6 (later stage):</i> -----	200
<i>Example 7 (later stage):</i> -----	201
<i>Example 8 (language):</i> -----	202
<i>Example 9: Process of selecting and developing memos 1:</i> -----	203
<i>Example 9: Process of selecting and developing memos 2:</i> -----	204
Appendix M: Diagramming -----	205
<i>Example 1:</i> -----	205
<i>Example 2:</i> -----	206
<i>Example 3:</i> -----	207
Appendix N: Interim Report-----	208
Appendix O: Comment Survey -----	220
Appendix P: Final Report -----	222

**List of Figures**

Figure 1: Services Pathway -----	63
Figure 2: The System -----	68
Figure 3: Parent Response -----	73
Figure 4: Supportive Context-----	78

## Acknowledgements

First and foremost, my sincerest thanks goes to the parents who contributed their time and expertise to this study. Their generosity is humbling and inspiring. I hope that through this project and future related efforts I am able to honour their contributions.

I would like to thank the partnering agency for their support, without which, this project would not be possible. In particular, the contribution of the agency representative was invaluable to the study process. The representative's professional commitment to the parents who participated in the study ensured a safe and successful process for all participants. Her willingness to commit time and effort to the research and to offer support and patience is sincerely appreciated.

I would like to acknowledge the instrumental guidance of my thesis supervisor, Professor Jessica Ball and my committee member, Professor Gordon Miller. Your support and encouragement were the 'light at the end of the tunnel'. To Professor J. Ball, thank you for knowing my weaknesses and pushing me to overcome them. I am stronger and better for it.

Finally, the most heartfelt thank you to my family and my partner, whose unconditional love and support carried me through the most difficult project I had ever undertaken. I am forever in your debt. And I love you.

## **Chapter I: Factors of service use by parents with mental illness**

### **Introduction**

Families affected by parental mental illness (PMI) face considerable challenges that can have detrimental effects on family members and overall family functioning (Mordoch & Hall, 2002; Nicholson, Biebel, Hinden, Henry, & Stier, 2001; Reupert & Maybery, 2007; Smith, 2004; Vostanis et al., 2006). The adverse effects of these challenges are significantly exacerbated when adequate and timely psychosocial supports (e.g., mental health supports, respite care, economic supports) are lacking (Bassett, Lampe, & Lloyde, 1999; Mensah & Kiernan, 2010; Mowbray, Oyserman, & Ross, 1995; Pfefferle & Spitznagel, 2009; Reupert & Maybery, 2007; Smith, 2004). Access to services for parents with mental illness (MI) is therefore imperative to the health and wellness of these families (Bassett, Lampe, & Lloyd, 1999; Reupert & Maybery, 2007).

A lack of services that directly target the needs of parents with MI and their families has been reported by American (Ackerson, 2003b; David, Styron, & Davidson, 2011; Hinden, Biebel, Nicholson, & Mehnert, 2005; Nicholson et al., 2001) and Australian researchers (Bassett et al., 1999; Huntsman, 2008; Reupert & Maybery, 2007). While no comparable statement could be found in Canadian literature, the situation is not necessarily better in Canada. First, the public mental health service delivery factors and trends in Canada, US and Australia are largely comparable (Kirby & Keon, 2004a); hence, it is likely that similar deficits exist across the three countries. Second, the Canadian system of mental health care has generally been acknowledged as under-resourced and poorly coordinated (Kirby & Keon, 2004b, 2006). Third, there is a startling lack of national attention on the needs of parents with MI and their families.

This is demonstrated by the omissions of these families from the prominent report on the state of the mental health system in Canada (Kirby & Keon, 2006) and the follow-up national strategy (Mental Health Commission of Canada, 2012). Consistently reported unmet mental health needs of the Canadian population (Statistics Canada, 2002, 2013), suggests that the needs of Canadian parents with MI and their families are not being adequately met within the public mental health services sector. This is alarming in light of copious accounts of risk of PMI to the child and family (Bassani, Padoin, & Vendhuizen, 2008; Hammen & Brennan, 2003; Mensah & Kiernan, 2010; Murdoch & Hall, 2002; Nicholson, et al., 2001; Pfefferle & Spitznagel, 2009; Reupert & Maybery, 2007; Smith, 2004; Sui Mui & Ying Suet Chau, 2010; Vostanis et al., 2006; Weissman et al., 2006).

What services and service engagement strategies are needed to meet the needs of parents with MI and their families? To begin to answer this question, factors that affect engagement of parents with MI with services would need to be identified. Identifying and addressing factors affecting access to services for parents with MI is especially relevant in light of the mounting evidence of the high human and public service system costs of MI (Canadian Institute of Health Information [CIHI], 2008; Cohen, McGregor, Ivanova, & Kinkaid, 2012; Federal, Provincial and Territorial Advisory Committee on Population Health [FPTACPH], 1999; Government of Canada, 2006; Health Canada, 2002; Jacobs et al., 2008). The perspectives of parents with MI on what is working well and on the changes are needed would also be important to consider.

The following literature review looks at the multiple levels of factors affecting use of services by parents with MI: individual and family level factors; as well as service provision and

system of care factors. Attention is given to studies that elicit the perspectives of parents with MI on engagement with services related to parenting.

### **Individual and family level factors**

Understanding individual and family level factors of service use can aid service providers in facilitating parental and family engagement with services (Sayal et al., 2010). It would seem, however, that investigations of these factors in the context of service use by parents with MI are lacking.

#### **Demographic factors.**

Little is known about demographic factors associated with various patterns of service use by parents with MI. Studies with ‘parents’ with MI have been limited mainly to mothers (Ackerson, 2003b; Nicholson, Nason, Calabresi, & Yando, 1999; Nicholson et al., 2001), which colours most of the available data as gender-biased and points to a large gap in the knowledge-base on fathers with MI (LeFrancois, 2012; Nicholson et al., 1999).

#### **Parental illness factors.**

Parental illness factors associated with patterns of mental health service use have received attention (Weissman et al., 2006). However, studies are predominantly descriptive and results highlight the complexity of association between parental illness factors and use of services. For example, service providers have identified acute symptoms of MI as a significant *barrier* to parental engagement with services (Boyd, Diamond, & Bourjolly, 2006; Franks, Henwood, & Bowden, 2007), while parents with MI seem to view exacerbated illness symptoms as a *motivator* for seeking treatment (Ackerson, 2003a; Nicholson, Sweeney, & Geller, 1998). Additionally, complex symptom presentation has, on the one hand, been linked to increased service

provision for parents with MI (Morrow et al., 2009), while on the other, it has been identified as interfering with access to *appropriate* intervention (Johansen & Sanmartin, 2011; Nicholson et al., 2001). Furthermore, receipt of what are considered appropriate treatment services for parents with MI may not directly translate into parental engagement with these services. Parents may cease or delay treatment in response to side-effects that impact their ability to parent (Ackerson, 2003a; Nicholson et al., 1998) or to treatment demands that interfere with parenting duties (Nicholson et al., 2001; Swartz et al., 2006).

Studies have found that mothers with MI identify the often competing demands of managing MI and parenting as a main barrier to engagement with services (Bassett et al., 1999; Boyd et al., 2006; Franks et al., 2007) and tend to view their own treatment needs as secondary to the needs of their children (Nicholson et al., 1998; Swartz et al., 2006).

### **Child factors.**

Children's mental health is likely to affect the mental health of the parents (Farmer, Burns, Angold, & Costello, 1997) and the overall functioning of families affected by PMI (Boyd et al., 2006; Nicholson et al., 1998), which may in turn influence parental help-seeking behaviours (Pfefferle & Spitznagel, 2009; Reid et al., 2006; Reid et al., 2011; Shanley, Reid, & Evans, 2008). However, the relationship between child factors and parental use of services seems to have been given attention exclusively in the context of child mental health services (CMHS). These studies (non-specific to the context of PMI) (Pfefferle & Spitznagel, 2009; Reedtz, Marti-nussen, Jorgensen, Handegard, & Mørch, 2011; Reid et al., 2006; Sayal et al., 2010; Shanley et al., 2008) show a complex relationship between child factors and service use that is influenced by multiple environmental factors (e.g., supports, family resources, family characteristics).

Nicholson et al. (2001) suggest further that the length of exposure of the child to PMI and overall effect of PMI on family functioning may be significant variables in use of CMHS by parents with MI. Others (LeFrancoise, 2012; Sui Mui, & Ying Suet Chau, 2010) have suggested that children's strengths, abilities and coping styles may influence family functioning in families where a parent has MI, which may in turn influence parental help-seeking.

### **Family factors.**

Family level factors, such as "family resources" (Boydell et al., 2006; Reid et al., 2011) and "family functioning" (Farmer et al., 1997; Reid et al., 2006) have been linked to parental use of mental health services (MHS). However, findings seem contradictory with respect to the effect of availability of family resources on service access and utilization. Low family resources have been identified as a barrier to community-based MHS (Beardslee & Gladstone, 2001; Bringewatt & Gershoff, 2010; Boydell et al., 2006). Similarly, availability of resources (Boydell et al., 2006; Reid et al., 2011) as well as an increase in resources (Gaskin, Kouzis, & Richard, 2008) have been demonstrated to facilitate use of MHS. However, the reverse relationship has also been demonstrated, wherein families with low resources have shown higher involvement with CMHS (Gaskin et al., 2008; van der Linden, Drukker, Gunther, Feron, & van Os, 2003). These discrepancies may point to mediating factors in the relationship between family factors and parental use of MHS that have yet to be considered.

### **Social supports.**

A family resource that has been identified by parents with MI as significant is availability of social supports (Ackerson, 2003a; Bassett et al., 1999; Boyd et al., 2006; Thomas & Kalucy, 2003). In particular, parents with MI associate strong support from family members and friends

with increased family coping (Ackerson, 2003a; Boyd et al., 2006); seem to rely on informal supports more than formal ones (Ackerson, 2003a); and assign especial value to supports for childcare during times of psychiatric crisis (Bassett et al., 1999; Thomas & Kalucy, 2003). Social supports have also been identified as a significant source of referrals to CMHS (Boydell et al., 2006; Reid et al., 2006) and may therefore be facilitative of parental access to services. As well, increase in social support has been identified as a main benefit of service use by parents with MI (Boyd et al., 2006; Nicholson et al., 1998; Swartz et al., 2006) and may therefore be a factor of continued service utilization.

Many parents with MI identify supports from family and friends as sources of both strength and stress (Ackerson, 2003a; Boyd et al., 2006; Nicholson et al., 1998). This suggests that benefit derived from family ‘resources’ may be dependent on mediating factors, such as quality of supports, length of time supports are utilized, as well as family and cultural dynamics.

### **Cultural factors.**

A family’s culture and ethnicity may affect understandings of cause, course, or treatment of MI (Compton, Kaslow, & Walker, 2004; Nicholson et al., 2001; Sui Mui, & Ying Suet Chau, 2010). In turn, these understandings may influence the styles of coping and help-seeking behaviours of persons affected by MI and their families (Compton et al., 2004; Sui Mui, & Ying Suet Chau, 2010). Understanding key features of a family’s culture, as well as being able to work within the boundaries of that culture, may build the capacity of a service to engage families and respond appropriately to their needs (Kerkorian, McKay, & Bannon, 2006; Pumeriega, Winters, & Huffine, 2003).

Increasing access to services for different cultural groups means increasing the cultural relevance of a service to the family (Kerkorian et al., 2006; Pumeriega et al., 2003). For example, Kerkorian et al. (2006) found that perceived cultural compatibility of a service was a factor in the perception of the quality of that service and determined subsequent use. Kerkorian et al. further suggested that “incongruence of cultural beliefs, values, and needs [of the family] with those inherent in traditional mental health programs” (p. 161) was a key barrier to services for families.

However, viewing culture as an evolving construct makes ‘cultural relevance’ difficult to gauge. For example, Sood, Mendez, and Kendall (2012) compared the factors of ethnicity and acculturation on their ability to predict understandings of the cause of MI and help-seeking preferences and found that acculturation was a better predictor of both. These authors suggested that attention should be given to “cultural constructs in addition to the sociopolitical categories of race and ethnicity” (p. 403). Pumeriega, Winters, and Huffine (2003) propose that a service that aims to be culturally relevant to a family may need to adopt an individualized perspective, treating each family as a unique amalgamate of individuals and experiences. More research on cultural factors of service use and help-seeking behaviours of different cultural groups has been encouraged by several investigators (Doyle, Joe, & Caldwell, 2012; Sood et al., 2012).

Overall, there is limited understanding of individual and family level factors influencing use of services by parents with MI. These gaps underscore the need for further investigation.

### **Service context factors**

Certain key service provision and system of care factors directly impact the ability of providers to offer services and the ability of parents with MI to engage with them.

### **Assessment and intervention factors.**

Adult mental health and social services often fail to either recognize the parenting role of adults with MI (Ackerson, 2003a; Bassett et al., 1999; Huntsman, 2008; Lees et al., 2002; Maybery & Reupert, 2009; Mowbray et al., 1995) or to adequately assess the needs of the children (Bassett et al., 1999; Maybery & Reupert, 2009; Reupert & Maybery, 2007) and family (Ackerson, 2003a; Bassett et al., 1999; Huntsman 2008; Lees et al., 2002; Maybery & Reupert, 2009; Mowbray et al., 1995). Gaps in recognition and needs assessment are also present in primary care contexts (Royal College of Psychiatrists [RCP], 2011). And while child mental health and child protection services are inherently cognizant of the parent, these services are often narrowly focused on the needs of the child (Ackerson, 2003b; Reupert & Maybery, 2007) or on parental deficits and failures (Ackerson, 2003b; Bassett et al., 1999; Reupert & Maybery, 2007).

Poor identification of the needs of the parent with MI and family, across service sectors (Ackerson, 2003b; Nicholson et al., 2001; Nicholson, Biebel, Katz-Leavy, & Williams, 2004; Maybery & Reupert, 2009) inevitably impacts both service provision and level of parental engagement. This oversight also contributes to a perpetually crisis-driven pattern of service access (Nicholson et al., 2001). Such pattern of access places significant stress on families and the system of care (Nicholson et al., 2001; Nicholson et al., 2004), which may lock both into a degenerative cycle.

Compounding problems with recognition and assessment of parental and family level needs of families affected by PMI, is a lack of understanding of what is appropriate intervention for these families (Hinden et al., 2005; Hinden, Biebel, Nicholson, Henry, Katz-Leavy, 2006; Huntsman, 2008; Nicholson et al., 2001; Reupert & Maybery, 2007). Targeted interventions have

been shown to lack theoretical basis (James, Fraser, & Talbot, 2007; Reupert et al., 2009; Reupert & Maybery, 2011), under-utilize supporting evidence (Nicholson et. al., 2001; Reupert et al., 2009; Reupert & Maybery, 2011), and undergo simplistic evaluations (Hinden et al., 2006; Nicholson, 2009; Nicholson et al., 2001; Reupert et al., 2009; Reupert & Maybery, 2011). Additionally, few services engage parents with MI in program evaluations (e.g. Hinden et al., 2005; Nicholson, Albert, Gershenson, Williams, & Biebel, 2008; Nicholson et al., 1998), despite the general acknowledgement in the literature that eliciting perspectives of parents with MI and their families on services increases understanding of service effectiveness and reach (Amedani & Hock, 2012; Kirby & Keon, 2006; MHCC, 2012; Nicholson, 2009; Reupert et al., 2009; RCP, 2011; Shanley et al., 2008; Smith, 2004; Sommers, 2007; Vostanis et al., 2006).

### **Service access factors.**

It has been suggested that access structures and processes are key service provision factors of parental engagement (Boydell et al., 2006; Lees et al., 2002); however, investigations of these factors only appear in the context of CMHS. For example, it has been shown that many parents face a complex, iterative process when seeking help options for their children (Reid et al., 2006; Sayal et al., 2010; Shanley et al., 2008). Capacity of points-of-first-contact for parents seeking MHS to respond to needs (i.e. to screen and refer) (Burnett-Ziegler & Lyons, 2009; Burnett-Ziegler et al., 2012; Manning, 2009; RCP, 2011); clarity and coordination of referral and intake processes (Lees et al., 2002; Ried et al., 2006; Sayal et al., 2010; Shanley et al., 2008); as well as broadening of service mandates and enrolment criteria (Boydell et al., 2006; Lees et al., 2002) have been suggested as factors that could increase services access by families affected by PMI.

Service access structures and processes are influenced by community size and location (Boydell et al., 2006; Pullmann, VanHooser, Hoffman, & Heflinger, 2010). Parents residing in a remote community will likely need to commit additional resources (such as transportation and childcare) to access services (Boydell et al., 2006; Pullmann et al., 2010). On the other hand, a small community may offer more ready access to informal supports (Boydell et al., 2006), which may in turn facilitate access to services for the parents. Additionally, localized services in small communities may offer more personalized professional supports (Boydell et al., 2006; Pullmann et al., 2010), which may increase service utilization and retention.

The availability and visibility of services within the community, have also been identified as important factors of service access (Boydell et al., 2006; Reid et al., 2006; Shanley et al., 2008). Availability of practical supports in the community (e.g., recreational and childcare services) (Boydell et al., 2006) as well as specialized services (Reid et al., 2006) have been identified as facilitative of parental help-seeking for CMHS. However, availability without coordination may interfere with timely or equitable access to services (Reid et al., 2006). Visibility of services, as indicated by the person's knowledge of and involvement with services, has also been shown to affect service access (Compton et al., 2004; Shanley et al., 2008). The relative in-visibility of mental health services (in comparison to medical or school services, for example) has been identified as a barrier to service access by parents with MI (Ackerson, 2003a; Bassett et al., 1999; Lees et al., 2002), parents seeking CMHS (Boydell et al., 2006; Compton et al., 2004; Sayal et al., 2010), as well as service providers (Alakus et al., 2007; Maybery & Reupert, 2009).

### **Service provider factors.**

An important factor in parental engagement with services is the ability of the service provider to engage parents with MI and their families (Ackerson, 2003b; Maybery & Reupert, 2009; Nicholson et al., 2001). The quality of the parent-provider relationships has been reported to influence parents' current and future engagement with MHS (Franks et al., 2007; Hinden et al., 2005; Kerkorian et al., 2006; Sayal et al., 2010). Specifically, trust in the parent-provider relationship as well as consistency of provider may be foundational to sustained parental engagement with services (Hinden et al., 2005), as well as to overall satisfaction with services (Bassett et al., 1999).

Unfortunately, many service users and their families continue to report being ignored or undervalued by service providers (Boydell et al., 2006; Kirby & Keon, 2006; Mueser & Fox, 2002). This may be a reflection of outdated and erroneous beliefs (Ackerson, 2003a; Maybery & Reupert, 2009; Mental Health Commission of Canada [MHCC], 2012; Nicholson et al., 2001), such as the belief that adults with MI are not likely to be parents (Nicholson et al., 2001). Inadequate training is another primary barrier to working with families affected by MI sited by service providers (Boyd et al., 2006; Maybery & Reupert, 2009). Adult mental health providers have identified lack of ability and qualifications to offer parenting or child-related supports (Alakus, Conwell, Gilbert, Buist, & Castle, 2007; Boyd et al., 2006; Maybery & Reupert, 2009). Child protection providers have reported insufficient mental health related knowledge and training (Alakus et al., 2007; Ackerson, 2003b; Hinden et al., 2005). Service providers across sectors reported having little information on available child and family services (Alakus et al., 2007; Boyd et al., 2006). Other barriers to successful engagement with parents with MI may be related to

workplace culture (e.g., problem-focused, crisis-driven) and limiting definitions of provider roles (Maybery & Reupert, 2009); or to logistical barriers, such as lack of time and resources (Alakus et al., 2007; Maybery & Reupert, 2009).

### **Discrimination of the mentally ill and associated factors.**

A primary barrier to engagement with services is pervasive society-wide discrimination against and stigmatization of the mentally ill (Government of Canada, 2006; Health Canada, 2002; Kirby & Keon, 2006; Lees et al., 2002; MHCC, 2012). Parents living with MI identify stigma as being a significant element of parenting with MI (Ackerson, 2003a; Nicholson et al., 1998) and a primary barrier to accessing services (Bassett et al., 1999; Boyd et al., 2006; Hinden, et al., 2005). Discrimination in professional settings may be a factor of low engagement of parents with MI with formal supports (Franks et al., 2007), as many professional services continue to be viewed as stigmatizing by persons with MI and their families (Bassett et al., 1999; Hinden et al., 2005; Kirby & Keon, 2006; Pullmann et al., 2010; Sommers, 2007).

The effect of stigmatization on families affected by MI may be perpetuated by the experience of socioeconomic deprivation (Franks et al., 2007; Government of Canada, 2006; Mensah & Kiernan, 2010; Mordoch & Hall, 2002; Nicholson et al., 2008), as a disproportionate percentage of persons with MI are living in poverty (Beardslee & Gladstone, 2001; Government of Canada, 2006; Staudt & Cherry, 2009; Weissman, 2006). The primary reason identified by parents for declining services are logistical barriers, such as costs of transportation and childcare (Alakus et al., 2007; Boydell et al., 2006; Pullmann et al., 2010; Reid et al., 2006).

For parents with MI, the experience of stigmatization is inextricably linked to fear of loss of child custody (Ackerson, 2003a; Alakus et al., 2007; Bassett et al., 1999; Lees et al., 2002;

Nicholson et al., 1998; Nicholson et al., 2001). This fear is not unfounded: loss of child custody for a parent with MI is common, as is the loss of contact with children once custody is taken away (Ackerson, 2003b; Hinden et al., 2005; Lees et al., 2002; Nicholson et al., 2001). Many parents with MI speak about their diagnosis being used against them in child custody battles (Ackerson, 2003a; Bassett et al., 1999). Consequently, parents may delay accessing services (including diagnostic and treatment services), despite exacerbated illness and overwhelming circumstances (Ackerson, 2003a; Bassett et al., 1999). The relationship between mental health and child protection services as potentially perpetuating a functional decline for the family affected by PMI deserves attention (Ackerson, 2003b; Nicholson et al., 2001).

Temporary loss of child custody may be unavoidable for many parents with MI (Hinden et al., 2005; Nicholson et al., 2008). How child protection concerns are handled by the provider are of crucial importance to the outcome (Bassett et al., 1999) and may be especially pertinent to parental engagement with services (Hinden et al., 2005). Services that offer support with contingency planning for possible psychiatric crisis may be imperative to minimize disruption to the family (Lees et al., 2002). Childcare at times of acute symptoms of illness or parental hospitalization has also been identified by parents with MI as most needed and helpful (Ackerson, 2003a; Bassett et al., 1999).

### **System-level factors.**

It is clear that common barriers to service provision and parental engagement arise out of system of care deficits. Underpinning much of the problems is pervasive lack of system resources dedicated to meeting the needs of families affected by MI (Kirby & Keon, 2004b, 2006). Lack of service resources is compounded by lack of human resources, especially in the mental

health service sector (Kirby & Keon, 2006), and in geographically remote areas (Boydell et al., 2006; Pullmann et al., 2010).

It has been argued that the issue of inadequate resources begins with inadequate policies to support the delivery of services (Maybery & Reupert, 2009; Nicholson et al., 2001). Not one healthcare policy in Canada speaks to the needs of these parents and families directly. Policies that commit to sustainable funding mechanisms for comprehensive services for families affected by PMI are urgently needed (Hinden et al., 2005; Nicholson et al., 2001).

## **Conclusion**

Research indicates that a majority of adults who live with MI are parents (Nicholson et al., 2001; Nicholson et al., 2004) who value and prioritize their parental role (Ackerson, 2003a; Bassett et al., 1999; Nicholson et al., 2001; Nicholson et al., 1998). The importance of comprehensive, accessible, and sustained services for families where a parent has MI has been strongly indicated (Ackerson, 2003b; Bassett et al., 1999; Hinden et al., 2005; Huntsman, 2008; Lees et al., 2002; Marsh, 2009; Nicholson et al., 2001; Vostanis et al., 2006). Unfortunately, the reality of the lack of such supports for families living with MI persists (Huntsman, 2008; Marsh 2009; MHCC, 2012). This reality seems reflective of gaps in understanding of individual and family level factors affecting service use in the context of PMI as well as of pronounced deficiencies in the service delivery and larger systems of care contexts (Kirby & Keon, 2006; Maybery & Reupert, 2009; Nicholson et al., 2001).

The foregoing literature review points to limited understanding of the perspectives of parents with MI on factors of service use. Studies that have sought direct reports from parents with MI in relation to services (e.g., Bassett et al., 1999; Franks et al., 2007; Hinden et al., 2005;

Nicholson et al., 2008; Nicholson et al., 1998) have yielded specific targets for improvement in service delivery. As well, eliciting the views of parents with MI about services has been shown to directly facilitate parental engagement with services (Ackerson, 2003a, 2003b; Bassett et al., 1999; Franks et al., 2007; Pumariega et al., 2003).

Overall, this literature review highlights the importance of further study of individual and family level factors affecting use of services by parents with MI, as well as underscores the importance of the service delivery and system of care contexts to the understanding of these factors. Research that represents the experiences of parents with MI of supports and services *from their perspective* has been indicated as potentially contributing to services becoming more responsive to the needs of their users and thereby more relevant, effective, and sustainable (Nicholson et al., 2004; Pumariega et al., 2003).

## Chapter II: Guiding Methodology

This study investigates the experiences of parents with mental illness (MI) of parenting services, *from the parents' perspective*. The driving questions that the study explores include: How do parents with MI engage with parenting services? What facilitates and deters access? What contributes to sustained use of services? What factors contribute to successful or unsuccessful service experiences? These are the starting points of this inquiry into the parents' experiences.

### Methodology

This study employs constructivist grounded theory (CGT) (Charmaz, 2006). CGT utilizes the strategies of grounded theory methodology (Glaser & Strauss, 1967; Strauss & Corbin, 1998) to examine “*how* — and sometimes *why* — participants construct meanings and actions in specific situations” (Charmaz, 2006, p. 130; original emphasis). CGT emphasizes process (i.e., actions/interactions and consequences/responses) as well as context (i.e., a set of conditions that influence process) in data gathering and interpretation of the studied social process (Bryant & Charmaz, 2007; Charmaz, 2006).

CGT is utilized to explore how (and to some extent, why) parents with MI engage with parenting services. CGT methodology was chosen in response to results of the literature review, which indicated a gap in the understanding of the process of engagement with services by parents with MI. The review further highlighted the relevance of the context of service delivery to the understanding of factors influencing the process of parental engagement. The method delineated here relies heavily on the representation of CGT by Kathy Charmaz (Bryant & Charmaz, 2007; Charmaz, 2006).

### **Gathering data.**

Data guide the development of ideas in grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1998). The researcher's initial thoughts on inquiry into a social process are treated as tentative starting points (Charmaz, 2006). The researcher follows the data and modifies the inquiry and/or the methods of data gathering as necessary (Charmaz, 2006). Therefore, while multiple methods of gathering data can be applied in GT (Charmaz, 2006), each method must be applied purposefully and flexibly (Charmaz, 2006; Strauss & Corbin, 1998). This study utilized focus groups and in-depth interviews as the main data gathering methods. These are discussed in detail in the following chapter on method.

### **Analysis.**

CGT employs the methods of coding and constant comparison (Glaser & Strauss, 1967) in the analysis of actions and processes (Charmaz, 2006). Analysis begins immediately by comparing segments of early data (Glaser & Strauss, 1967). Comparison allows for similarities and differences to become apparent (Charmaz, 2006; Glaser & Strauss, 1967) as well as for certain actions or conditions to begin to stand out as salient (Charmaz, 2006). The researcher interprets these patterns with analytical codes that stand in for what is happening in the data (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Constantly comparing sets of data as well as data and emerging codes helps to identify properties of a substantive process (Charmaz, 2006; Glaser & Strauss, 1967). Comparison also illustrates relationships within and between the analytic codes, which are then developed into theoretical representations for what is happening in the data (Charmaz, 2006; Glaser & Strauss, 1967). As patterns emerge that link codes to other codes, the interpretation becomes more selective and analytical (Charmaz, 2006; Glaser &

Strauss, 1967; Strauss & Corbin, 1998). Some codes will subsume others and others will be raised to the level of categories (or main ideas) that begin to form an emerging theory (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998).

Sequential comparison helps to systematize the process of analysis, while constant comparison — of data with data, data with codes, codes with codes, and later, codes with categories — keeps the researcher immersed in the data (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). In this way, the categories are systematically developed and the emerging theory is firmly rooted in the data (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998).

### **Coding.**

Charmaz (2006) identifies two main stages in coding: initial and focused. During initial coding the analyst sifts through the data word-by-word, line-by-line, incident-by-incident, remaining open to all possibilities inherent in the data (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). This detailed exploration of all possible meanings can guard the researcher against imposing his or her own meanings onto the data (Charmaz, 2006). This process can also identify new patterns, contrasts, and ideas that will guide further data gathering and analysis (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). The meticulous stage of initial coding ensures that the researcher remains grounded in the data and subsequently produces interpretations that, “crystallize participants’ experience” (Charmaz, 2006, p. 54).

Focused coding is the process of developing the most salient ideas and of theoretical integration of these into an emerging theory (Charmaz, 2006). It involves selecting codes that most closely and concisely represent the data and make the most analytic sense (Charmaz, 2006). Codes that have more analytical reach than others are then raised to the level of categories that

begin to form the emerging theory (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Through this process, meanings in earlier data that had remained hidden to this point may be illuminated, which may prompt a recoding of earlier data or returning to the field to collect more data to develop the new ideas (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). It may become apparent that certain codes or categories have not been fully developed or that gaps in logic exist — both issues will need to be addressed through further analysis and/or data gathering (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Hence, coding is a non-linear process (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998) that requires that the researcher be prepared to reexamine his or her ideas in light of what the data indicate (Charmaz, 2006).

Constructivist researchers attend closely to the language used in coding and emergent analysis (Charmaz, 2006). Charmaz (2006) asserts, “Coding should inspire us to examine hidden assumptions in our own use of language as well as that of our participants” (p. 47). At times, participants can offer “telling terms” (Charmaz, 2006, p. 57) that convey meaning that is significant and unique to their experience (Charmaz, 2006). Using these as in vivo codes can help to convey the participants’ worlds in a manner that resonates with their peers and other audiences (Charmaz, 2006; Padgett, 2008). Furthermore, the use of specific language structures in coding can help the researcher attune to particular ways of seeing the world (Charmaz, 2006). For example, Charmaz (2006) argues that the use of gerunds in coding prompts looking at incidents of data as processes and facilitates sticking closely to participants’ experiences, meanings and actions.

### **Memo-writing and analytic aids.**

From the start of the research process, grounded theory (GT) analysts engage in memo-writing to aid in developing codes and categories, articulating ideas, and organizing the research process (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Memos are treated as “partial, preliminary, and provisional” (Charmaz, 2006, p. 84). In addition to being a critical step in developing analytic ideas that are firmly grounded in the data, memo-writing can help to organize the research process and provide a record of each step, increasing the credibility of the emergent theory (Charmaz, 2006).

Sorting, diagramming and integrating of memos on categories are interrelated processes that aid analysis (Charmaz, 2006). These processes illustrate and refine theoretical links between categories and clarify the rationale of the emerging theory (Charmaz, 2006). They can also aid the creative process (Charmaz, 2006) and help situate the analysis in larger contexts (Charmaz, 2006; Strauss & Corbin, 1998). The aim is a cohesive and meaningful narrative that follows the theoretical links between categories and illustrates the studied process (Charmaz, 2006).

### **Theoretical sampling and saturation.**

Theoretical sampling occurs at a later stage of analysis and data gathering (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Through theoretical sampling the researcher seeks to fill out the properties of categories, identify relationships between categories, and define the range of the variation within the process represented by a category (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Hence, theoretical sampling is sampling for analytical ideas, rather than observable experiences or events (Charmaz, 2006). This may involve adding new participants with experiences that may illuminate an aspect of the developing

theory or asking earlier participants new questions that arise out of the analysis (Charmaz, 2006). The aim of theoretical sampling is to develop an insightful theoretical understanding of a social process (Charmaz, 2006).

Theoretical sampling is a corrective tool for analytic problems, such as insufficiently developed categories or weak links between them (Charmaz, 2006). It ensures that the analysis and the emerging theory are firmly grounded in the data (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Hence, theoretical sampling increases both the analytic power and the credibility of the GT (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998).

When comparative analysis yields no new insights (or properties of categories) and the boundaries of categories have been clearly defined, the process reaches a state of *theoretical saturation* (Charmaz, 2006; Glaser & Strauss, 1967; Kirby, et al., 2006; Strauss & Corbin, 1998). Kirby et al. (2006) define saturation as the point at which “the overall *analytical* pattern ‘steadies’ or ceases to shift, as new parts of the analysis are added” (p. 223; added emphasis). Theoretical saturation is not seeing the same pattern in the data (i.e., repetition of events or statements), but rather seeing the same pattern in the analytical *interpretations* of the data (Charmaz, 2006; Kirby, et al., 2006). Charmaz (2006) and others (Kirby, et al., 2006) caution against premature decisions regarding saturation and advocate for ongoing vigilance for new insights.

### **Evaluating CGT.**

Charmaz (2006) suggests that a constructivist researcher aims to construct a *credible, original, meaningful, and useful* interpretation of a social process. Credibility arises out of systematic application of the method (Charmaz, 2006). It involves: “intimate familiarity with the setting or topic” (Charmaz, 2006, p. 182); “strength of the data” (Kirby, Greaves, & Reid, 2006,

p. 241); the depth and range of categories as well as logical links between them (Charmaz, 2006); and agreement of participants with conclusions (Charmaz, 2006; Kirby et al., 2006). Originality is an outcome of the researcher's creative and fluid engagement with the data (Charmaz, 2006; Strauss & Corbin, 1998). Meaningfulness is the product of situating the theory in its contexts and linking theoretical concepts with fundamentally human concerns (Charmaz, 2006).

Usefulness may be the most important evaluative criteria of CGT, not only from the pragmatic standpoint (i.e., that it *can* be applied), but also from the political (i.e., that it *will* be applied) (Charmaz, 2006; Denzin, 2010; Kirby et al., 2006). Charmaz and others (Denzin, 2010; Kirby et al., 2006) argue that the process of generating knowledge (or research) is a political act, because what is generated will be used (Charmaz, 2006; Denzin, 2010; Kirby et al., 2006). Hence, researchers must clearly state how they intend the knowledge they generate to be utilized, or risk their work being misrepresented or misused (Denzin, 2010; Charmaz, 2006; Kirby et al., 2006). Ultimately, research should "contribute to a better world" (Charmaz, 2006; p. 185).

### **Summary.**

A defining feature of GT is that data gathering and analysis are done simultaneously and sequentially (Bryant & Charmaz, 2007; Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). The GT method ensures that the product is a substantive theory, firmly grounded in the participants' experiences and worldviews (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998).

A key point about doing GT is that any method employed is a means towards an end (Bryant & Charmaz, 2007; Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). In CGT, the researcher is viewed as an extension of the method and hence, as pivotal to the research

process and product (Bryant & Charmaz, 2007; Charmaz, 2006; Thornberg, 2012; Williamson, 2006). The researcher must ensure that the theory he or she produces is both credible and useful (Bryant & Charmaz, 2007; Charmaz, 2006).

### **Limitations**

The study design has notable limitations with respect to its adherence to the CGT methodology. First, it elicits only the parents' perspective on engagement with services. It also limits its immersion into the contexts that influence the parents' process. A comprehensive CGT study would aim to gain insight into the process from multiple perspectives (Charmaz, 2006), such as those of family members, service providers, and policy makers. It would also aim to immerse as fully as possible into the relevant contexts (Charmaz, 2006; Kirby et al., 2006), such as structures and operations of multiple agencies involved in supporting parents with MI.

Additionally, the application of theoretical sampling and the ability to reach saturation are expected to be affected by the small sample size of the study.

Acknowledging these issues, the study is not intended to produce a comprehensive theory of the experiences of parents with MI of engagement with parenting services, but rather to offer a substantive interpretation of localized data.

### **Chapter III: Methodological considerations**

The following section outlines the methodological considerations specific to recruiting participants and gathering data, including the role of reflexivity in the research process.

#### **Recruiting participants**

The study utilized agency-based recruitment. The main benefit of agency-based recruitment is relative ease of access to participants, especially in terms of the time invested to locate participants and establish initial rapport (Abrams, 2010). There are limitations of agency-based recruitment. This strategy excludes parents with MI not connected to the agency, who are more likely to be the “hard to reach group” (Abrams, 2010, p. 544). As selection of participants is done by the gatekeeper, the researcher has much less control over this process (while on the flip side, researcher selection bias is minimized) (Abrams, 2010). Further, as recruitment and data gathering takes place in the agency during regular operating hours, anonymity of participants cannot be assured. For the same reasons, it may be difficult to ensure confidentiality (Abrams, 2010). Furthermore, inadvertent coercion of agency service users into participation may occur (Abrams, 2010). Parents may feel that provision of agency services may be compromised if they decline to participate or they may feel obligated to participate to honour their relationship with the agency gatekeeper and other staff members.

Careful planning and consultations with the agency gatekeeper are suggested as mitigating strategies for pitfalls associated with agency-based recruitment (Abrams, 2010). (Refer to the chapter on Method for a detailed discussion of risk-mitigating strategies.)

### **Theoretical sampling and sample size.**

Theoretical sampling was the main recruitment strategy in phase two of data gathering (refer to Data gathering section of the chapter on Method for details): selection of participants followed an iterative process guided by what the analysis of earlier data indicated (Charmaz, 2006; Padgett, 2008). Theoretical sampling is intended to continue throughout the research process, until a decision is reached regarding theoretical saturation or ‘theoretical sufficiency’ (Charmaz, 2006): a point at which no new insights are gained from analysis (Charmaz, 2006; Glasser & Strauss, 1967; Strauss & Corbin, 1998).

Sample size in grounded theory (GT) cannot be predetermined, as it is dependent on when analysis reaches the point of saturation (i.e., is based on the quality of data produced) (Charmaz, 2006; Glasser & Strauss, 1967; Strauss & Corbin, 1998). Sample size in GT impacts credibility of the product (Charmaz, 2006; Kirby, Greaves, & Reid, 2006; Padgett, 2008): the smaller the sample, the less likely the theory to capture the full breadth and complexity of the studied experience (Charmaz, 2006). Credibility of small sample GT studies is especially dependent on the extent of its claims relative to sample size (Charmaz, 2006).

The application of theoretical sampling and the ability to reach saturation is discussed in the Limitations section of the chapter on Method.

### **Gathering data**

Considerations specific to the application of the methods of focus group, semi-structured interviews and ethnographic observations are discussed in the following sections. Considerations for applying reflexivity in the research process are also outlined. (The application of the data gathering methods is discussed in the Method chapter.)

### **Constructing focus groups.**

Focus groups are commonly used in exploratory research (Krueger, 1988; Padgett, 2008). Careful planning is essential to group success (Linhorst, 2002; Kirby, Greaves, & Reid, 2006; Krueger, 1988; Padgett, 2008; Rauktis, Feidler, & Wood, 1998). General strategies for group composition, site selection, and facilitation (see Kirby et al., 2006; Krueger, 1988; Padgett, 2008) as well as suggestions for facilitating groups with persons with MI (Rauktis et al., 1998) are discussed.

Suggestions for what numbers allow for group success vary. For example, Rauktis, Feidler and Wood (1998) found that groups of seven or eight resulted in the most productive, free-flowing discussions, while groups of three to five resembled multiple individual interviews conducted at the same time. Conversely, Kirby, Greaves and Ried (2006) suggest “four to five people for approximately two hours of interaction” (p. 145). “The size of a focus group should be large enough to generate diversity of opinions but small enough to permit everyone to share in the discussion” (Padgett, 2008, p. 100).

Homogeneity of groups, based on certain key characteristics of participants typically facilitates disclosure (Kirby et al., 2006; Krueger, 1988; Padgett, 2008). The groups conducted by Rauktis et al. (1998), the common experience of public mental health services was more important than demographic factors in group cohesion.

Another common aim for the composition of groups is a greater degree that participants are unknown to each other, as familiarity is thought to inhibit disclosure (Kirby et al., 2006; Krueger, 1988; Padgett, 2008). Conversely, Rauktis et al. (1998) argued that familiarity in their groups increased the level of comfort, which these authors noted to be an essential element to

group success. Facilitator skills are essential to mediating potential effects of familiarity in the group (Kirby et al., 2006; Krueger, 1988; Padgett, 2008).

Rauktis et al. (1998) also established that the site chosen for the group influenced the type of information produced. They found a varied effect in groups that were held at the service agencies: the participants' attention was either focused on services offered at those sites, or strategically diverted from those services for fear of reprisal for negative comments. Rauktis et al. suggested generalizing the discussion about services to mediate these effects. These authors noted that convenience of location to the participants (e.g., easy access by public transit) may be the most important consideration. Overall, the greater the comfort of the participants, the more likely the focus group is to be experienced as beneficial by the participants and the richer the data produced (Rauktis et al., 1998).

The role of the moderator is central to a successful group process (Aglias, 2011; Kirby et al., 2006; Krueger, 1988; Padgett, 2008; Rauktis et al., 1998). This may be especially true of facilitation of group interviews with vulnerable populations, such as persons with MI (Padgett, 2008; Rauktis et al., 1998). The most important task of the researcher in the group is to facilitate safety and comfort of participants and mitigate potential risks (Kirby et al., 2006; Krueger, 1988; Padgett, 2008; Rauktis et al., 1998).

Focus groups can have several limitations. Linhorst (2002) noted that logistic of organizing the group can be challenging, the number of questions that can be addressed is small, and interviewer skill in leading a group is essential. Additionally, while the "stimulus of ...interaction" (Rauktis et al., 1998, p. 90) can facilitate the formulation and expression of opinions (Krueger, 1988; Rauktis et al., 1998), intense interactions can also change participants' views to

fit the dominant view of the group (Linhorst, 2002) or silence those who think differently (Kirby et al., 2006). The greatest limitation of focus groups is the inability of the researcher to guarantee that confidentiality will be upheld by co-participants (Kirby et al., 2006; Krueger, 1988; Linhorst, 2002; Padgett, 2008).

Focus groups can promote feelings of powerlessness, if participants come to believe that their situation is poor and will not improve (Linhorst, 2002). Groups that evaluate services can also create expectations for actions that may not be realized (Linhorst, 2002). Conversely, it has been argued that anticipated emotional harms to participants may be unfounded (Ahern, 2012; Ogden, 2008). To understand participant perception of harm during research on ‘sensitive topics’, Ahern (2012) conducted a focus group with past research participants and found that sources of harm identified by participants were unrelated to the experience of negative or strong emotions during the interviews and “the real benefits of participation overwhelmingly outweighed the ‘harms’” (p. 675).

There are several potential benefits to the participants from engaging in focus group interviews (Linhorst, 2002; Rauktis et al., 1998). For example, Linhorst (2002) concluded that groups could empower, educate, and have “therapeutic effects” (p. 223). Rauktis et al. (1998) and others (Nicholson et al., 1998) also noted the supportive nature of focus groups. Rauktis et al. (1998) concluded, “Individuals with a serious and chronic psychiatric disability have few opportunities for sharing, support and acceptance, and a FGI [focus group interview], albeit briefly, can be a setting for this to occur” (p. 88).

### **Constructing in-depth interviews.**

The second main data gathering method of the study was semi-structured interviews, partially shaped by predetermined questions that explore ideas salient to the main topic (Padgett, 2008). Semi-structured interviews allow for an in-depth exploration of participants' experiences and perceptions (Charmaz, 2006; Padgett, 2008) and constitute "a useful method for interpretive inquiry" (Charmaz, 2006, p. 25). The interviewer retains flexibility in how the inquiry is conducted and in what questions are asked or withheld (Charmaz, 2006; Padgett, 2008). Questions need to be "sufficiently general to cover a range of experiences and narrow enough to elicit and elaborate the participant's specific experience" (Charmaz, 2006, p.29). The interviewer can ask additional questions to probe an area in depth, clarify, elicit contrasts, and follow 'leads' or spontaneous insights (Charmaz, 2006; Padgett, 2008).

GT interview questions are guided by the analysis of data: as the analysis becomes more focused, the questions become more dense and salient (Charmaz, 2006; Kirby, Greaves, & Ried, 2006). Hence, interview questions in GT cannot be entirely predetermined (Charmaz, 2006; Kirby et al., 2006). Charmaz (2006) and others (Kirby et al., 2006) suggest that questions be critically examined for bias and intent.

The interviewer must be aware of elements that influence the interview process, such as setting, tone, pacing and emphasis of questions (Charmaz, 2006; Kirby et al., 2006; Padgett, 2008). The interviewer must also attune to the participant-interviewer relationship and be able to address any potentially problematic dynamics (Charmaz, 2006; Kirby et al., 2006).

The primary task of the interviewer is to ensure the safety and relative comfort of each participant (Aglias, 2011; Kirby et al., 2006; Padgett, 2008). Charmaz (2006) suggests general

guidelines for interviewing persons who may have experienced trauma, discrimination, or silencing: 1) always consider participants' comfort over generating data; 2) listen as much as probe; 3) close the interview on a positive note by asking questions that are likely to elicit positive responses; and 4) take time to close — never do so abruptly.

Along with the general good practice of ensuring that all participants feel validated, respected, and appreciated for their contribution (Charmaz, 2006; Kirby et al., 2006; Padgett, 2008), the interviewer must be able to handle situations during which a participant is experiencing strong emotions (Aglias, 2011; Charmaz, 2006; Padgett, 2008). Charmaz (2006) suggests that the researcher attempt to understand this experience from the participant's perspective and "validate its significance to this person" (p. 30). Similarly, Aglias (2011) argues for a non-assuming approach. Aglias suggests that asking about the reasons for conveying an incident that is difficult to talk about may invite the realization of hidden strengths. Padgett (2008) reminds the researcher that he or she should never aim to elicit strong emotions, "only to create a safe place for their expression" (p. 118). Padgett and others (Aglias, 2011; Charmaz, 2006; Kirby et al., 2006) advocate for approaching engagement with participants from a position that affirms them as autonomous beings who are experts on their needs and capable of meeting these.

### **Observing and recording in field notes.**

Ethnographic observation can illuminate "context and content, meaning and action, structures and actors" (Charmaz, 2006, p. 25). Ethnographic observations are especially pertinent to the understanding of contextual factors associated with the studied process (Charmaz, 2006; Williamson, 2006). GT's focus on processes and analytic interpretations can help the researcher attune to what is salient or beneath the surface, such as taken-for granted meanings and actions

or tacit understandings and assumptions (Charmaz, 2006). Keen observations of self and others guide the research process, including how the researcher positions herself or himself in the process (Charmaz, 2006; Kirby, Greaves, & Ried, 2006; Padgett, 2008). Field observations also enhance understanding of the audio-recoded data and may lead to more focused follow-up with participants (Padgett, 2008).

Fieldnotes are the researcher's notes containing detailed observations of the setting and its players (Kirby et al., 2006). The notes also contain anecdotes as well as the researcher's thoughts, which "become progressively focused on key analytic ideas" (Charmaz, 2006, p. 22) and form the basis for analytical memos (Charmaz, 2006; Padgett, 2008). Padgett (2008) suggests writing fieldnotes in real time or within 24 hours of the event to increase recall. Avoiding personal or theoretical filters in compiling fieldnotes is imperative to the integrity of the data (Charmaz, 2006; Kirby et al., 2006; Padgett, 2008).

### **Applying reflexivity.**

"The researcher's scrutiny of his or her research experience, decisions, and interpretations" (Charmaz, 2006, p. 188), is integral to the integrity of the research process and product (Charmaz, 2006; Kirby, Greaves, & Ried, 2006). He or she must be able to identify personal, social, and political influences behind all decisions throughout the research process or risk unwittingly letting these influences (rather than the data) guide data gathering and analysis (Breuer & Roth, 2003; Charmaz, 2006; Kirby et al., 2006; Thornberg, 2012). Kirby et al. (2006) argue further that researchers must make visible their positions of power and be fully transparent in their allegiances.

## **Conclusion**

The study design incorporated the considerations listed in this chapter. The guiding principle of planning and application of study procedures was that participant comfort and safety superseded methodological considerations. The application of the study methods is discussed in detail in the following chapter.

## **Chapter IV: Method**

This chapter outlines the study method in four sections. The first section presents recruitment strategies and outcomes pertaining to participant criteria, initial selection, sample size, theoretical sampling, and screening of participants. The second section presents consent for study procedures and results. The third section outlines the application of data gathering methods. The final section delineates the limitations associated with the application of the method and how these limitations impact the study findings.

### **Recruitment**

#### **Participation criteria.**

Participants were residents of Vancouver and Greater Vancouver, from varied demographic and cultural backgrounds. The main inclusion criteria were that participants self-identify as ‘parents with mental illness (MI),’ as having children up to 18 years of age, as having had contact with parenting services, and as having access to adult mental health services throughout their participation in the study.

The term ‘parent’ as used in the participation criteria was inclusive of biological parents, custodial and non-custodial parents, adoptive parents, step-parents, or other long-term primary caregivers. This criterion was intended to capture all persons who view their parental role as a significant aspect of their lives.

Participants self-identified as a ‘parent with MI’. No proof of diagnosis was requested; however, the initial selection of participants (see Initial selection section below) was based on their engagement with adult mental health services, for which a diagnosis is required (Vancouver Coastal Health [VCH], 2013, Locations & Services: Adult Mental Health section). The focus of

recruitment was on ‘parents with MI’ rather than on ‘parents with mental health challenges or problems’. Whereas the latter terms may be preferred by some parents, the former was chosen to elicit responses from parents who have had experiences with public mental health services. These services are targeted at persons who have a diagnosed mental illness (e.g., Coast Mental Health, 2014, About Coast section; VCH, 2013, Locations & Services: Adult Mental Health section) or who are seeking a diagnosis (e.g., BC Mental Health and Substance Use Services, 2013, Provincial Programs and Services: Adult Clinics and Services section). The focus on parents with MI was intended to ensure that results would be applicable to the context of these services. The study participation criterion regarding type or number of diagnoses was left open. This is consistent with the enrolment criteria for most public mental health services (e.g., Coast Mental Health, 2014, About Coast section; VCH, 2013, Locations & Services section, Adult Mental Health section).

Participants had to have had contact with parenting services. Type of contact included in this criterion: being in receipt of services or attempting to access services; having had or having attempted access to services in the past; as well as having been offered access and having declined. Self-reporting was considered sufficient. ‘Parenting services’ were loosely defined as generic parenting supports (e.g., childcare, generic parenting program), basic targeted supports (e.g., respite services, home support), or specialized supports for parents with MI (e.g., specialized parenting groups, professional consultations). The final definition of parenting services was left up to the participants to capture the range of services that parents considered part of the parenting services context.

Participants also had to self-report having current access to an adult mental health professional. This criterion was included to ensure that participants had adequate mental health supports during the research process. Exclusion for reasons of priority of illness stabilization or access to appropriate treatment was written into the design. This criterion is discussed in detail in the screening section.

The following parent groups were excluded: short-term caregivers (such as short-term foster parents); professional care-providers; parents of adult children (19 years plus); parents who do not currently identify as being a ‘parent with MI’. These parent groups were assumed to be significantly different from each other and from the intended study sample, with respect to needs and the process of engaging with services. While these groups would have presented an interesting comparison to the study sample, this was beyond the scope of this study.

A final participation criterion was that all participants were fluent in the English language. All communications were in English, as translator services were cost prohibitive for the partnering agency (agency representative, personal communication, March 26, 2014). This is considered a major limitation of the study design.

### **Initial selection.**

Recruitment was conducted with the help of the partnering agency, a national community mental health organization with local branches serving the communities of Vancouver and the Greater Vancouver Area. Initial selection was done by the agency representative — a team leader and program coordinator with the partnering agency. This person acted as the agency gatekeeper, selecting potential participants, who were parents accessing the services of the partnering agency.

The benefit of recruiting through a community agency was ease of access to participants.

Potential risks of agency-based recruitment (refer to Methodological considerations chapter)

were discussed with the agency gatekeeper, based on the suggestion by Abrams (2010) that raising awareness with gatekeepers may partially mitigate these risks. *The names of the partnering agency and the agency representative are withheld from the thesis and all other public reports or presentations on finding to protect the anonymity of study participants.*

Selecting participants from service users attached to the partnering agency was strategic, to ensure that participants were well supported through the research process. Services provided by the agency include crisis response, parent education, and referral (agency representative, personal communication, January 31, 2014). Further, the parents engaged with the partnering agency are referred through Vancouver Coastal Health (VCH) Adult Mental Health Program (VCH, 2013, Locations & Services section, Adult Mental Health section). This increased the likelihood that participants had access to adult mental health services during the research process.

Initial selection was based on the main participation criteria. The agency representative contacted each potential participant to introduced the study. During this conversation, the representative explained that participation is voluntary and is in no way connected to current or future services provided by the agency. I provided the representative with a script for the initial conversation with potential participants to ensure that these key points were covered during initial contact. Interested parents received a poster and a brief letter introducing the study (Appendix A); this was done in a confidential manner to minimize the identification of participants by agency staff.

Participants expressing interest were asked for permission for me to contact them (by whatever means they preferred) at a time that was most convenient for them. The agency representative further assured the parents that all personal contact information would be kept in strict confidence by the researcher (me) and would only be used by for the purpose of contacting them to discuss their interest in the study.

Recruitment for phase one lasted nine weeks, from September to December of 2014. This was longer than the anticipated timeframe and was due primarily to the availability of participants. The agency representative and I maintained ongoing communication throughout this time via phone and email. All precautions were taken to ensure that participant confidentiality was strictly maintained. (Phase two of recruitment is discussed in the following section on Theoretical sampling.)

### **Sample size.**

Initial search (October-November 2014) yielded six confirmed participants and two undecided. Five agreed to participate in a focus group, however two were not available until the following year (2015); one chose to be interviewed one-on-one. The second round of recruitment (November-December 2014) yielded four confirmed participants; two agreed to participate in the focus group and two chose to be interviewed one-on-one. Following several attempts to connect with participants and coordinate availability for the groups, six participants were retained from the first round of recruitment and two from the second round. In total, eight participants were recruited for phase one of data gathering: three for the first focus group; three for the second group; and two for individual interviews. Participants' availability was the deciding factor in sample size.

### **Theoretical sampling.**

Participants were selected for a follow-up interview, based on theoretical sampling considerations (Charmaz, 2006). Small sample size affected application of theoretical sampling, as cautioned by Charmaz (2006). Four participants from phase one were selected for phase two; however only two were available within the allotted timeframe (April to June 2015). While the proposal accounted for this possibility by the addition of new participants to the study sample, the difference between projected and actual timelines for completion of recruitment made the application of this strategy impractical. Hence, all participants in phase two took part in the initial phase of data gathering. The limitations of a premature end to recruitment for phase two of data collection are discussed at the end of this chapter.

### **Screening.**

All initial contact with interested parents was done by phone (the parents' preferred means of contact). The initial screening interviews included an introduction to the study's purpose and process: researcher's intentions for the findings, participant voluntarism, handling of information, limits to confidentiality, the data gathering process; and the researcher's role in ensuring participant safety and comfort (Appendix A). Screening included questions based on participant criteria and asked about participant preferences of research activities (focus group or individual interviews). The purpose of initial conversation was to facilitate informed consent, clarify participant expectations, and identify potential risks or barriers to participation.

### ***Ongoing screening.***

Agllias (2011) argues that treating safety assessment as continuous enhances participants' safety in the interview process. Following this recommendation, ongoing screening was incorporated into the study process. Participants were informed of the process of 'ongoing check-ins'. I would contact each parent the day before the planned group or interview and ask about changes to his or her health, mental health supports, or life stressors. I would also ask the parent to assess perceived ability to participate. I approached the screening for potential risks to participant safety in the research process from a position that affirms participants as autonomous beings who are experts on their needs and capable of communicating these, given the opportunity. Following is an excerpt from the ongoing screening script (Appendix B).

To check in, I will ask you the following questions. Have you had any recent changes in your illness or your life that might make it difficult for you to participate? On a scale of one to ten (one being very poor), how are you feeling about your ability to manage doing the interview? Keeping in mind that participating may be somewhat stressful or difficult, are you feeling up to going ahead?

I encouraged participants to communicate their needs pertaining to the study at any point in the research process.

While the ongoing screening for potential risks to participants' safety in the research process relied heavily on self-reports, this strategy was complemented by my clinical skills, specifically my ability to assess for compromised cognitive or emotional states related to mental illness. Predetermined indicators that the parent was experiencing a period of instability related to the MI were: a) the parent reports that he or she lacks access to adult mental health services; b) the parent rates his or her ability to manage doing the interview as four or below; or c) participation interferes with treatment priorities or is detrimental to the parent's wellbeing. If any one of

the indicators would have been present; I would have had a discussion with the parent about how to support him or her to participate at a later time. The decision to request that the participant withdraw from the data gathering process would have been made in consultation with the research team, adhering to confidentiality guidelines.

All participants reported a high level of ability (six and above) throughout the study; all continued to have access to adult mental health supports. I agreed with participants' self-reports. No participants were excluded for the aforementioned reasons.

### **Consent to participate.**

I arranged in-person meetings to discuss and sign consent for study with all interested parents. Parents who declined participation were no longer contacted; their contact information was securely stored until the end of the research process, at which time it will be safely disposed.

The consent for study discussion were at a location chosen by the participants (e.g., participants' home, public place, or the agency's branch office). Communicating consent information in person was intended to ensure, to the best of my ability, that each participant was fully informed on the study prior to signing consent. Ahern (2012) suggests that engaging with participants around consent increases participant awareness of the research process, opens up opportunities to discuss participant expectations, and can increase the development of trust between the participant and the researcher. Additionally, the ability to 'translate' the more formal language of the consent form, offer clarifications, and answer any questions may mitigate reservations about participation based on possible misperceptions regarding the research process or potential harms (Ahern, 2012).

Prior to commencing the consent discussion, each parent was reminded that participation is voluntary and can be withdrawn at any time (including during or after this meeting). Information about the study's purpose, methods, participant demands, potential risks, and dissemination of findings was communicated in the consent for study form and accompanying discussion (Appendix B). Attention was given to risks to participants "based on comprehensive information about foreseeable harms" (Ogden, 2008). Potential risks communicated were: the experience of strong emotions or emotional stress; potential for breach of participant confidentiality when participating in a focus group; and risk associated with limits to confidentiality. Risk mitigating strategies were also clearly outlined. Additionally, participants were informed about how information was going to be handled during and after the research. All personal information and data collected during the study (e.g., written notes, audio recordings, computer files) were securely stored under lock and key or password protected. All information collected during the study (with the exception of reports on findings) will be safety and permanently destroyed after study completion. Finally, anticipated means of dissemination of findings were outlined (refer to Disseminating findings section of the Findings chapter).

Ten participants signed the consent for study form; two later declined participation. The consent meetings ranged from 45 minutes to one and a half hours with an average of one hour. The meeting locations were chosen by participants: five meetings took place at a coffee shop convenient to the participants; four at participants' homes; and one at the local partnering agency branch.

Some participants mentioned that they would have been overwhelmed by the content of the consent form had I not taken the time to explain the consent in person. Most took the oppor-

tunity to clarify study parameters and potential risks of participation (e.g., identification of participants in reports, timelines for study completion, and distribution of information post study completion). Few participants also inquired about my reasons for doing the study and intentions for findings. Majority volunteered their motivation for taking part in the study. Some reported that talking about their experiences was part of the process of recovery or “moving forward”. Unanimously, participants expressed their desire to help service providers understand their experiences. They relayed the hope that their stories would help other parents with MI have an easier path towards effective and relevant supports.

A separate consent form (Appendix B) was signed by one participant who wished to be identified by the first name (rather than a chosen pseudonym) in all recordings of data and reports on findings. The option of being identified by their real name in all reports on findings was made available to all participants to respect their right to choose how they are identified and whether they would like to be credited to the information they provide. Prior to the one participant signing the form, I discussed the risks associated with being identified in the research and inquired about that participant’s expectations for how information will be disseminated and used post research. This participant stated zero concerns with being identified in the data or in reports on findings as the reason for not wishing to choose a pseudonym.

All participants accepted the \$20 compensation at the end of each consent meeting, with one exception. This participant stated altruistic intentions for doing the research as reason for declining compensation.

### ***Ongoing consent.***

I adopted an ongoing approach to consent, based on the suggestion by Rauktis, Feidler and Wood (1998) that this would increase the likelihood that participants are fully informed of study expectations and risks throughout their engagement. Ongoing consent was combined with ongoing assessment of participants' safety (refer to Screening section of this chapter); both were referred to throughout the study as 'ongoing check-ins'. The Ongoing screening and consent form is presented in Appendix B.

I informed participants that these check-ins are an opportunity to discuss any concerns related to participation or decline participation for any reason, as well as to clarify the next activity and ask question about or offer comments on the study. I explained that check-ins are part of my commitment to ensure that participants' consent is fully informed, participation is entirely voluntary, and participants' safety and comfort is in the foreground of research tasks and processes. The ongoing check-in strategy was outlined in full in the consent form (refer to Consent for study form in Appendix B).

### **Data gathering**

Data was collected over two phases. Phase one was exploratory; that is, aimed at generating areas of relevance, from the parents' perspective. Focus group questions were employed at this stage (refer to Focus groups section below). Phase one consisted of two focus groups and two individual interviews. The option of an individual interview as an alternatives to the group was made available to ensure that participants had a choice of how they contributed to the study, as well as to ensure that the study did not exclude based on participants' comfort level with the focus group process. Phase one lasted from mid October 2014 to beginning of February 2015.

Collection began with individual interviews (i.e., chosen alternative to the focus group). Two participants chose this option. The first individual interview was completed in October 2014; the second interview in November 2014. The second interview was completed in two parts, each lasting one and a half hours. The two focus groups were done at the end of November 2014 and beginning of February 2015.

Phase two of data collection was aimed at a more focused exploration of the relevant themes identified in the first phase. Theoretical sampling was the main recruitment strategy. Participants from phase one were recruited for phase two. Phase two consisted of three individual interviews with two participants. This phase lasted from beginning of April to the end of May 2015. Due to extended timelines for completion of recruitment for phase one, phase two was not fully realized. This is considered a major limitation of the study (see Limitations section at the end of this chapter).

Data was also collected from participants via request for comments on the interim report (Appendix D). The report was distributed in the beginning of July 2015 and participants were given until mid August to submit comments. (Refer to Member checking section of this chapter for more details.)

The outcomes of the application of the focus group, individual interviews, observations, and member-checking methods are discussed in the following sections.

### **Focus groups.**

Two focus groups were held, as planned. Recruitment for the groups took longer than anticipated, mainly due to challenges in coordinating participants' availability. (Refer to Sample

size section for details on recruitment.) The first group was conducted at the end of November 2014; the second in beginning of February of 2015.

The groups were held at the local branch of the partnering agency. This site was familiar and accessible to most participants. To facilitate access to the group, the partnering agency offered compensation to participants for transportation and childcare on site. Compensation for transpiration was accepted by all participants; childcare was not needed. The agency representative aided two participants with transportation, to mitigate inconvenience. Each participant received a gift card of \$25 and a Thank you card for their time and contribution at the end of the group.

The agency representative and I consulted on group composition and planned process prior to group commencement. The main task of planning for the groups was to facilitate safety of group participants. Participants were made aware of all potential risks and risk mitigating strategies prior to the group (refer to Screening and Consent sections of this chapter). Additionally, participants were asked to wear name-tags with chosen pseudonyms and use these during the discussion. (The one exception was the participant who opted to be identified by the first name. However, the other participants were not made aware of this choice.) Further, agency staff were informed that the parents are participating in a parent group to maintain a level of anonymity for research participants.

### ***Composition.***

Each group consisted of three participants, the agency gatekeeper, and the researcher as the lead facilitator. The suggestion of Kirby, Greaves and Ried (2006) of “four to five people for approximately two hours of interaction” (p. 145) was followed in the design. However, due to

difficulties in coordinating participant availability for the groups, the intended group size was not achieved. After consultation with the research supervisor (J. Ball, personal communication, November 16, 2014) and the agency representative (personal communication, November 14, 2014) the decision was made to go ahead with three participants per group. This was done to accommodate interested participants and to maintain the momentum of the research process.

The expected key similarities between focus group participants were that participants were parents with MI who had contact with professional supports for parenting. Selection of participants was not based on demographic or illness-specific characteristics. Rauktis, Feidler and Wood (1998) found, “the experience of using public mental health services seemed to cut across degree of disability, age, gender and level of education” (p. 84). The decision not to collect demographic and illness-specific characteristics also ensured minimal intrusion into participants’ lives. The decision not to base group selection on demographic criteria did not appear to affect group cohesion.

Recruitment from one community-based agency increased the likelihood of familiarity between participants; however, to the best of the agency representative’s knowledge, participants were not known to each other prior to the group. One participant raised concerns related to familiarity during an ongoing ‘check-in’; however, seemed reassured by the strategies aimed at mitigating risks to group participants (as discussed below).

### ***Process.***

Each group was approximately two and a half hours in length. Time for social engagement and refreshments was scheduled in at the start of the group and during the break, following

suggestions by Rauktis et al. (1998) and others (Kirby et al., 2006) for creating a comfortable milieu.

The opening questions for the groups were: *What types of parenting services have you come in contact with? What has been your experience with parenting services?* Followup questions were: *What has contributed to successful experiences? What has contributed to unsuccessful experiences?* These questions explored key elements of the parents' experiences with services, from their perspective. The wrap up questions were: *What would you say to service providers? What would you say to parents who are looking for parenting services?* These questions elicited the parents' expert opinion on what is most important in (a) providing a successful service experience and in (b) managing the process of engaging with services.

The small group size affected group process. At times, the groups resembled individual interviews, with each participants taking turns to speak on a topic, rather than engaging in dialogue. A similar effect was noted by Rauktis et al. (1998). Krueger (1988) suggests that focus groups offer the opportunity to the researcher to observe the effects of interaction on generation of information. This opportunity was not fully realized. Conversely, the small group size allowed participants time to tell their stories as well as to gain and offer empathic support. The small group size also enabled easier transcription of recordings and negated the need for a timekeeper.

I led the group with the agency representative acting as a co-facilitator. I facilitated the main discussion, including ensuring equal opportunity for disclosure and keeping the conversation on course, i.e., utilizing basic facilitation skills (Linhorst, 2002; Kirby et al. 2006; Padgett, 2008). Leading the group included managing situations when participants were experiencing strong emotions — another key facilitator skill (Agliias, 2011; Padgett, 2008). I utilized empathy

and validation; approached participants from a strength orientation (i.e., viewed the participants as capable and resilient individuals) and monitored the effect of emotional expression on all participants. I intervened with questions that oriented the participant to their abilities and strengths — following suggestion from Aglias (2011) — and opened up space for participants to offer emphatic support to each other.

Challenges in group facilitation were experienced, as anticipated. These included: ensuring that every participant had equal opportunity to speak without cutting off those who had more to say or forcing participation on others; maintaining the group on topic (e.g., general experiences with services versus in-depth description of a program); balancing providing space for participants to offer supports to each other (e.g., distribute information about resources) with adhering to the research goals; as well as asking questions that generated quality data (e.g., prompting to explore an area in depth versus directing attention off topic). Overall, challenges in group facilitation were manageable and offered opportunities for learning and reflection.

The agency representative's familiarity with participants and established rapport was expected to increase the comfort level and safety of group members. The agency representative's presence in the groups proved invaluable. She took the lead in reminding parents of safety and self-care strategies at the end of each group. She also offered casual individual support to participants during breaks and after the groups, offering opportunities to discuss the group process and its impact. To the best of my knowledge, none of the participants accessed support from the agency representative (related to the group process) after the groups.

As suggested in the literature (see Kirby et al., 2006; Krueger, 1988; Padgett, 2008), I led a discussion about group rules pertaining to confidentiality before the start of each group. I pre-

sented the anticipated group process and outlined facilitator roles. I also reminded participants of their ability to stop at any time and to request additional supports. The agency representative and I led a discussion on supports and self-care strategies at the end of both focus groups. This was especially emphasized after one emotionally charged group. Participants of this group referred to the process of expressing emotion during the group as cathartic and stated that emotional expression increased the feeling of being supported and accepted by fellow participants. All participants affirmed understanding of the importance of safety and self-care.

Additionally, I followed up with all group participants within the first two days following the groups (with most contacts occurring in the first 24 hrs following the group). These conversations were by phone and typically lasted ten minutes, but ranged from five to thirty minutes. I assessed participants' safety utilizing strength-oriented questions as a way to build on participants' strengths, in the manner suggested by Agllias (2011). I inquired whether the participants accessed or planned to on accessing available supports and whether they needed additional information or resources. I reminded participants that the agency representative was available for additional support at any time throughout the study. All participants reported that they were doing well and viewed the group as an overall positive experience.

### ***Summary.***

Focus groups were intended to explore perceptions of a group of parents with MI of parenting services. It became clear early on that the groups were more than a means towards an end. Primarily, the groups offered participants the opportunity to share their stories as well as to relate to their peers and to offer their support, both emotional and practical (e.g., sharing of resources). All participants explicitly identified the groups as supportive. Some also expressed a desire to

reconvene as a group after the completion of the study. This was consistent with the findings of other social researchers (e.g., Linhorst, 2002; Nicholson et al., 1998; Rauktis et al., 1998). Further, participants readily embraced the opportunity to speak to providers and their peers through the study. These findings seem consistent with the conclusion of Rauktis et al. (1998) that, “advocacy, information, and empowerment were beneficial to the consumers who participated in FGIs [focus group interviews], and would not have occurred using other evaluative methods” (p. 91).

### **Individual interviews.**

Two interviews were conducted with two participants in the first stage of data gathering. The interview with one participant lasted approximately one and one half hours and was done at the participant’s home (i.e., preferred location). The interview with the other participant was conducted in two parts, each lasting one and a half hours (for a total of three hours) and was at a private room of a coffee shop chosen by the participant. The extended time of the second interview facilitated trust in the researcher-participant relationship and increased the level of safety and comfort of the participant in the research process.

Three interviews were done with two participants in phase two of data gathering. Participants were selected based on theoretical sampling considerations. Each interview lasted approximately one and a half hours and was held at the parent’s home (i.e., preferred location).

Participants received \$20 compensation at the end of each interview. One parent refused cash as compensation but accepted small gifts of appreciation (e.g., tea and a jar of honey). I explained that gifts from a guest to the host are part of my cultural upbringing and represent my appreciation of the participant’s kindness and generosity.

Interview questions in phase one of data collection were the same as focus group questions (refer to Focus groups section above) with more opportunities for prompts. Interview questions in the second stage of data gathering were based on the analysis of data from the first stage. These questions aimed to fill in gaps identified in the development of codes and links between codes and categories. Questions were also selected for relevance to participants' experiences, i.e., filled in gaps in individual accounts. Questions were developed before each interview (see Appendix C for examples). Not all of the predetermined questions were utilized in the interviews. This decision was based on relevance of themes to participants (established based on verbal and emotional content of participants statements) and the dynamics of the interview process (e.g., pace, expression of emotion). During one interview, content that elicited a strong emotional response from the participant was avoided. This decision was made collaboratively with the participant.

Safety of interview participants was continuously assessed, as planned (refer to Ongoing assessment and Ongoing screening section of this chapter). During the ongoing check-ins, both participants rated their ability to do the interviews as six or higher (ten being highest) and stated that they were keen to carry on with the study. Participant safety was at the forefront of interview moderation. Following the interviews, I informally followed up with participants. Both reported that they were doing well.

### **Observations.**

Observations occurred in the contexts of the partnering community agency and interview settings.

The partnering agency is at the heart of collaborative efforts between multiple government and non-profit social services and mental health agencies to build a responsive network of community resources to support families affected by MI (agency representative, personal communication, January 31, 2014). Towards this end, this agency hosts a monthly roundtable of community organizations (agency representative, personal communication, January 31, 2014). Participation in the roundtable offered an opportunity to observe the current context of local service delivery, including latest efforts towards a continuum of services for families affected by MI. These observations enhanced the understanding of the influence of local service delivery factors on the process of parental engagement with services for parents with MI. These observations were not recorded or treated as data. The decision to exclude these observations from data was made in collaboration with the agency representative to ensure that roundtable members were not taxed with the tasks of becoming research participants (e.g., signing consent forms). The potential for research tasks to compromise members' active involvement in the roundtable was the deciding factor in excluding observations from the study.

Observations of interactional dynamics during the group and individual interviews aided the research process and analysis. Observations of non-verbal communication between group participants and between participants and the researcher were helpful to identifying how each participant was doing in the research process (e.g., Is the participant comfortable? Are there concerns pertaining to this process that are being left unsaid?) Observations of participants body

language; tone, cadence, and volume of voice; and chosen pace of speaking were documented in fieldnotes and treated as data in the analysis.

### **Member-checking.**

Participants' agreement with findings increase research credibility (Charmaz, 2006). The interim report on findings was sent out to interested participants via preferred means (e.g., email, mail) at the beginning of June 2015. A brief comment survey was sent with the report, as well as a self-addressed envelope with postage. (The interim report and the comment survey are available in Appendix D.) Participants were invited to comment in any way that suited them best (e.g., mail, email, phone), by mid August 2015. Participants' comments guided the focus of the ongoing analysis and highlighted key findings.

### **Limitations**

There were several challenges encountered in implementing the study as originally planned. First, recruitment of participants from one agency with one gatekeeper limited the study sample. This was largely due to gatekeeper's error in projection of the size of the pool of potential participants. Hence, the methodological guidelines for sample size (see Kirby, Greaves, & Ried, 2006) were superseded by the practical considerations of availability of participants.

Second, participant availability for recruitment tasks (initial contact by the gatekeeper; initial contact and screening interview with the researcher, and the consent meeting) and coordination of availability for the focus groups extended the projected timeline for phase one recruitment. This, in turn, shifted projected deadlines for completion of phase one and two of data collection. The initial small sample size, participants' availability for phase two, and the pressure of the deadline for completion necessitated a premature end to recruitment for phase two. This sig-

nificantly affected the application of theoretical sampling and the ability to reach saturation. It is likely that my inexperience in conducting interviews, specifically in asking questions that produce quality data, compounded this limitation.

Acknowledging these limitations, this study does not claim general relevance or extended reach; rather, it is a pilot study that identifies some of the features of the landscape of parenting services, *from the perspective of parents with MI*. Research that has the means to overcome the limitations of the current study and further explores parenting services from the perspective of parents with MI is strongly encouraged.

## Chapter V: Process of Analysis

Each interview and focus group was transcribed within the first week of the completion date. Analysis began immediately following transcription of the first interviews. As new data was coming in, it was transcribed and incorporated into the analysis, according to the constant comparative method (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Analysis focused on processes: actors and actions/interactions; contexts that influence actions; and consequences of actions/processes (that become the context for the next set of actions).

### Coding

Analysis began with initial (a.k.a. open) coding of data (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Each transcript was reviewed and data was separated into sections. Each section composed of information that logically fit together or seemed to represented a theme in the data (or parts of a theme). Sections ranged from one to several sentences in length. Segments were labeled and used for referencing in the focused coding stage. This helped to organize the process of analysis.

The data in the segments were openly coded. Word-by-word and phrase-by-phrase coding was utilized selectively: certain words or phrases were targeted because they a) were emphasized by the participants (through use of voice or repetition); b) contained possible tacit meanings (e.g., colloquialisms); or c) indicated processes or contexts related to the inquiry. Sections of data were also compared to illuminate the process of meaning-making; and words and phrases within the segments were analyzed to reflect this process (i.e., ensuring that the meanings of words and phrases were interpreted in the context of what was being said). (Examples of initial coding can be found in the Appendix E.)

Initial coding of data from later interviews was more selective (e.g., contained less free-association), as certain codes that had already been developed were applied. Remaining open to possibilities in the data was balanced with maintaining momentum in the research process. Relevance to the participants — as gaged from emphasis in the data and previously stated motives for contributing to the study (refer to Consent section of the chapter on Method) — was the guiding principle in selecting possibilities in the data.

Focused (a.k.a. selective) coding (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998) involved examining initial codes for patterns and relevance to the developing analysis. Some of the initial codes were selected as more representative of the data and others were dropped. Codes that were selected were developed for range of characteristics (Strauss & Corbin, 1998); some codes were subsumed by others (i.e., added to the development of other codes) (Charmaz, 2006; Strauss & Corbin, 1998). Codes were linked by logic or patterns in the data (Charmaz, 2006). Some codes were raised to the level of categories, if they were seen as sufficiently representative of the emerging idea (Charmaz, 2006); alternatively, new terms for categories were introduced.

Focused coding was done in two main stages. The early stage involved sifting through the initially coded transcripts, selecting codes for relevance, and applying constant comparison method: linking data with data, data with codes and codes with codes (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). The later stage involved pulling out codes from the data and developing these through the use of memos and diagrams. Data sections and participant identity codes were used to track the links between analytical codes and data. Track changes edit-

ing option of the Pages (Mac) program was used as an organizational aid. (Examples of focused coding can be found in Appendix E.)

### **Memo-writing and diagramming**

Coding was accompanied by writing memos. Memos focused on processes and contexts illuminated by the data. Memos were analytical (i.e., focused on developing codes and categories; selecting and linking codes and categories) (Charmaz, 2006; Strauss & Corbin, 1998) and reflexive (i.e., a critical scrutiny of a part of the research process, including the role of the researcher) (Charmaz, 2006; Kirby, Greaves & Ried, 2006). (Examples of memos can be found in Appendix E.)

Memos from the initial coding stage were imbedded directly into the analysis of each section of data. These often followed the process of free-association or brainstorming. Some of the initial memos were selected for relevance to the evolving analysis and compiled into categories of the emerging theory (e.g., ‘system’ processes; exceptional processes; parents’ responses). The process of selecting and developing memos continued parallel to the developing analysis. Here again, track changes option of the Pages (Mac) program was used as an organizational aid. (Examples of the process of selecting and developing memos can be found in Appendix E.)

Memos were instrumental in developing codes and organizing ideas. Analysis continued to loop from memos to codes; changes in codes and categories were reflected in memos and vice versa. Later memos resembled writing drafts and became the basis for the presentation of findings. (Example of memos from the later stage of analysis can be found in Appendix E.)

Diagramming was another integral element of analysis during the focused coding stage. Diagramming illuminated links between codes and categories and aided the process of selecting

the most relevant codes and categories. Diagramming was also instrumental in organizing and representing the developing ideas. (Examples of earlier diagrams can be found in Appendix E.)

### **Language**

The use of language was closely attended to throughout the analysis. Meanings of codes were examined and reexamined for tacit implications, nuances, and power dynamics (Example of a memo developing the language of codes can be found in Appendix E.)

Gerunds were used in coding, following the suggestion by Charmaz (2006). This was noted to create a sense of movement in the data, which aided the flow of analysis (i.e., guarded against rigid and finite thinking). The use of gerunds also facilitated viewing the process of generating data as an ongoing process of relating and meaning-making. This highlighted the importance of creating a safe space for participants to tell their story. It also heightened awareness of the research as part of the data generating process, as well as the role of the researcher in this process.

## Chapter VI: Findings

### **Introduction**

The findings are presented in three sections. The first section (*Engaging with parenting services*) highlights the parents' process of accessing services (outlined in *Getting through the gate* and *Being granted access* sections) as well as the impact of this process on the participants and their families (*Enduring the process*). It also presents participants' views on the context and processes of parenting services (*Seeing the big picture*) and participants' responses to this context. It contains three figures — Figure 1: Services pathway; Figure 2: The System; and Figure 3: Parents response. The next section (*Supporting Parents*) illustrates the supportive context and processes; these are represented graphically in Figure 4: Supportive context. The last section (*Tearing Down Walls - Building Bridges*) lists participants' recommendations.

The presentation of findings utilizes qualitative descriptors of *few*, *some*, *many*, *most*, and *majority*. In this report, these words represent the following range of numbers: *few* is three to four; *some or many* is five to six; *most or majority* is six to seven. To clarify, the number of participants does not necessarily correspond to the weight (i.e., the relative importance) of the data, which was also gauged by the frequency of the theme or pattern in the data, participant consensus, and the emotional emphasis placed on a theme or pattern by participants. Key processes and contextual factors of the parents' process of engagement with services represent ideas with the most weight; these are italicized throughout the text.

The second to last section of this chapter identifies how findings have been disseminated up to this point as well as expectations for future distribution. The last section briefly outlines my intent for findings.

## **Engaging with parenting services**

### **The parenting services context.**

The context of parenting services described in this report encompasses Vancouver, Burnaby and Richmond. Participants identified two main service domains: government and community. These domains were distinguished by perceived authority over the family, demands on the parent, and approach to service delivery. Participants identified the following primary government services — referred to by the majority as “the system”:

- Ministry of Children and Family Development (referred to as “The Ministry”)
- Ministry of Social Development and Social Innovation (MSD)
- BC Housing
- Adult Mental Health Services (primarily psychiatric services)

Individual schools (elementary and high school) and school-based programs as well as pro-bono legal services (i.e., Legal Aid) were also referred to as part of “the system,” though appeared less frequently in the parents’ accounts. Additionally, half of the participants had contact with Family Court (FC); however, they tended to refer to “court” as a satellite of parenting services.

Government services had the most power to affect the parent and family, especially as they held the monopoly on essential aid (e.g., income and housing subsidy). These services placed the most demands on the parent and enforced the expectation of compliance, frequently through what the parents perceived to be punitive measures.

Community services consisted of government contracted agencies (CAs) and non government contracted organizations (COs). Community services were perceived as having the most

supportive (e.g., collaborative) approach to service delivery. However, they held less power than government agencies to affect change for the parent and family.

COs were non-profit agencies that provided the most low-barrier access to services. However, they appeared to be the least able to provide tangible benefits to the parent and family and were the least frequently mentioned.

Contracted agencies (CAs) — mainly contracted by “The Ministry” — muddled the domain boundaries. While CAs were non-profit community organizations, majority of their services were inaccessible through the community, i.e., only accessible through “the system”. CAs were also frequently viewed as government representatives — a role that was reinforced by contractual restrictions on access and obligations to monitor the parent and family on behalf of the government agency. On the other hand, the CAs' approach to service delivery aligned them with other community-based services (COs).

### **Falling through “the gap”.**

Parents who began their search for services in the community encountered a services “gap”: missing services and missing links (a) between services and (b) between parents and services. Essential services (e.g., housing and income subsidy, psychiatric services) were strictly the domain of “the system”. While many other potentially beneficial services (e.g., counselling for the parent and family) — despite being community-based — were only accessible to parents who were ‘in’ “the system” (i.e., had an open file with a government agency).

Community-based parenting services that did not require that the parent was ‘attached’ to a government agency also restricted access. Some based eligibility on the parent’s income, opening access only to low-income families. Others limited access based on the parents’ cultural or

ethnic affiliation. Some services were inaccessible due to limiting operations to day-time hours and/or failing to eliminate barriers (e.g., did not provide childcare or assistance with transportation).

Parents also encountered outdated, “scattered,” and missing information about parenting or mental health services. Parents spoke of having to do extensive research and source out information from all available avenues, including from parenting groups and peer networks. They described service databases as incomplete and difficult to navigate. They identified service providers (across domains) as poorly informed and often unable to offer appropriate referrals. Many parents talked about offering information to providers, rather than the reverse. Additionally, parents found community organizations (COs and CAs) failing to reach out. This appeared to be especially true of agencies that geared their services towards persons and parents with MI.

Some parents were able to commit to the “full time job” of actively seeking services. Others spoke of having no such opportunity. This was especially true of working parents; parents who had extensive family obligations; and those who had few (or no) family/personal supports. While the apparent lack of an information ‘system’ and relative invisibility of mental health services made accessing community services a frustrating experience for all parents, these deficits ensured that parents who had barriers to actively seeking services were disconnected from community supports.

Many parents identified a profound sense of isolation that accompanied the process of searching for services in the community. Parents identified feeling unable to meet personal, family, and societal expectations of ‘good parents’. Some parents also questioned whether asking for help meant that they were failing as parents.

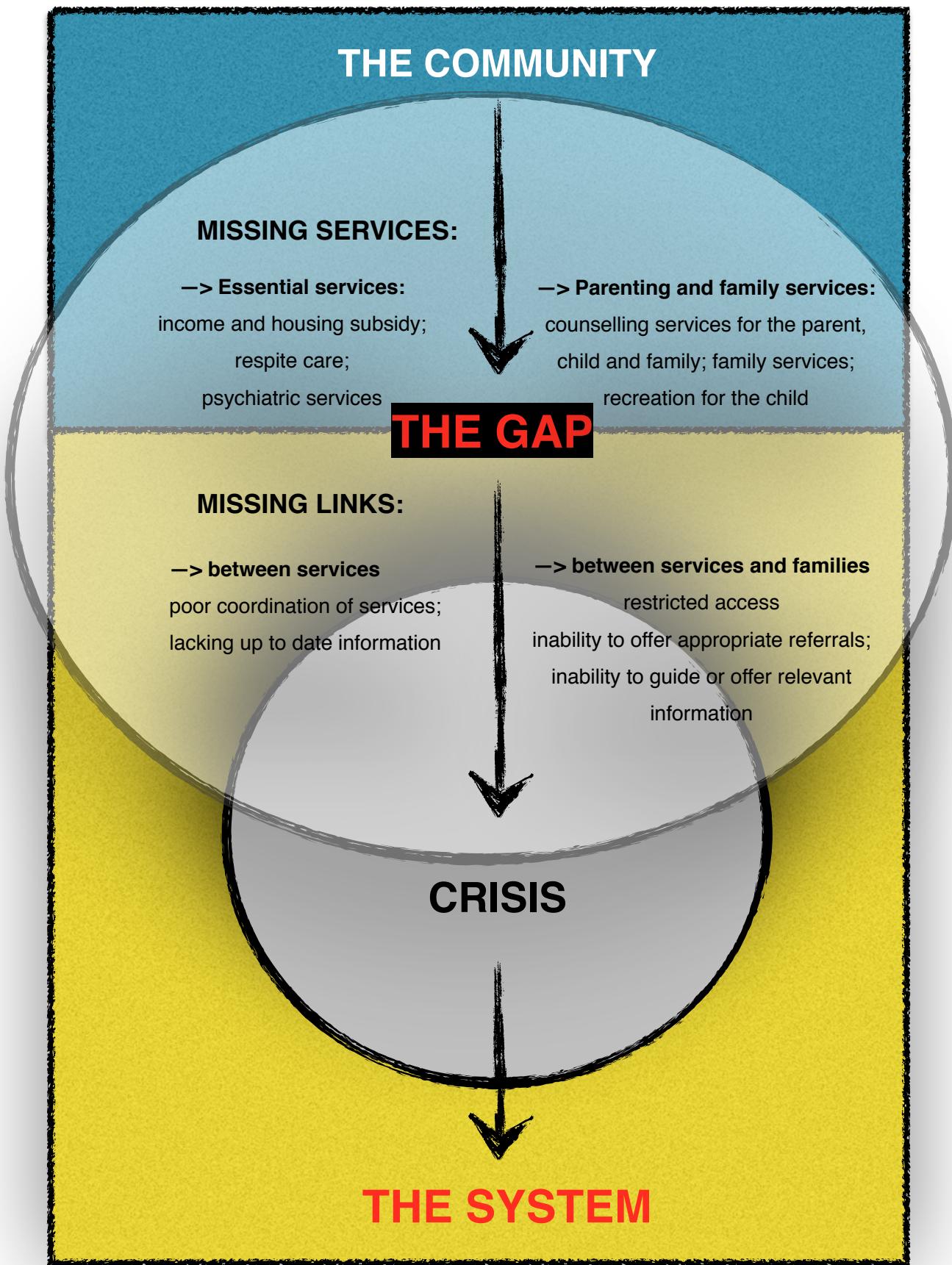


Figure 1: SERVICES PATHWAY

*Falling through the services “gap”* was an overwhelming experience for the parents and families. Placing barriers to access or failing to remove existing barriers exhausted already depleted personal reserves and exacerbated often significant challenges (e.g., divorce, losing a job or housing, recovering from illness or injury). This often resulted in crisis for the parent and family, increasing the risk of a ‘mental break’ or relapse of symptoms of MI for the parent. Hence, *falling through “the gap”* often necessitated contact with emergency services. Typically, this path led directly into “the system” (Figure 1: Services pathway).

### **Experiencing “the system”.**

Entering the system was “the only way” to get access to the following services:

- housing and income subsidy
- psychiatric and therapeutic services for the parent and child
- and respite care

It was also the only way to gain access to the majority of services provided by contracted agencies (CAs), such as counselling for the parent and family, parent support groups, and certain recreational opportunities for the child.

Irrespective of participants’ prior experience with the system, all were aware of the potentially devastating impact of entering the system on the family (e.g., loss of child custody) and saw this as their “last resort”. It was clear from all accounts that the parents had done everything in their power to avoid this path. Ironically, attempting to avoid contact with the system led parents quicker to it, as they sacrificed their health and wellness in attempts to surmount the challenges of providing for their children and family without adequate supports.

### ***Getting through the gate.***

Whether the parents entered the system through emergency services (i.e., were in crisis) or they requested access (i.e., were acting preemptively), the system initiated what many parents viewed as a crisis response: *profiling* based on risks and problems, and *triaging* based on indicators of ‘extreme need’.

Parents experienced the system as *gating* services: granting or denying access based on the criteria of ‘extreme need’. Parents’ accounts demonstrated that access was dependent on the system provider’s interpretation of whether the parent ‘fit’ the typical system profile of the “extreme case”. If the parent’s presentation did not ‘fit,’ access was refused or restricted. If the parent was returning to the system, access was dependent on the interpretations contained within the old file.

Typically, the system placed the onus on the parents to prove that they were really suffering. Access to services was further dependent on the parents’ ability to negotiate the administrative process of *proving need*. This process involved complicated steps (e.g., multiple forms, appointments with specialists). Parents found that most system providers did not offer guidance and typically passed the parent on to another provider. Parents described being bounced like a “ping pong” from source to source and at times being given contradictory or erroneous information. Few community providers aided the parents in this process; those that did, typically did not have government contracts.

Having to ‘jump’ through administrative ‘hoops’ was exhausting and discouraging. Parents found that there was little regard in this process for the effects of mental or physical illness (e.g., low energy, pain, distress) or for the emotional impact on the parent of entering the system

(e.g., having to depend on system ‘handouts’). Parents reported that inability to meet process demands was viewed by system providers as evidence that the parent and family had alternative resources or as non-compliance — both interpretations jeopardized the parents’ access to services.

***Being granted access.***

*Getting through the gate* via emergency services meant an influx of services that was described as overwhelming. This process assured that the parent was contacted by “The Ministry” (MCFD). It also typically facilitated parents’ access to psychiatric and social work supports. Parents described the sudden appearance of services as starkly contrasting their silence in the community, prior to the parent being in crisis.

*Getting through the gate* did not guarantee services, however. At times the system failed to provide, despite clear indications of need. Parents spoke of being denied income subsidy at critical times in their lives, e.g., after leaving an abusive partner or losing the only means of income; as well as being denied access to safe family housing, despite the family being homeless. Parents had been on the wait list with BC Housing for years prior to being granted access and a few were “still waiting”.

Parents also spoke of being offered services that didn’t come close to what they were requesting or needed. For example, all parents on income assistance had to regularly access food and clothing banks. Parents identified the system as failing to adequately meet their families’ basic needs and as providing inadequate solutions to problems, i.e., *band-aiding* rather than addressing problems.

*Being granted access* also frequently meant being *passed on* to a different department and/or another provider. It was not unusual for parents' files to change hands several times during their time 'in' the system. Changing providers meant having to start over: having to yet again prove need, comply with more administrative demands, and attempt to build a new provider-parent relationship. *Changing hands* was experienced as difficult and discouraging, especially as this sometimes compromised access to services.

Majority of system services were offered through contracted agencies (CAs). *Being granted access* meant receiving tangible benefits that supported the parents' recovery and strengthened the family. However, CA services came with 'strings attached'. CAs acted as informers to their government contractor: *monitoring* and reporting on parents' progress.

All parents, however, spoke of CAs offering excellent services, despite this handicap. CAs' main weakness was identified as restricting access, especially cutting off access once the parent was no longer 'in' the system. While some CAs attempted to negotiate an alternative service arrangement with the parent and family (e.g., charging for services on a sliding scale), most became inaccessible to the parent and family 'outside' the system.

### ***Enduring the process.***

Parents experienced the system and majority of system providers as *controlling and disempowering* (Figure 2: The System). For all parents accessing the system meant *losing choice, privacy, and voice*. Parents endured system providers *negating (and often removing) their rights and responsibilities* (e.g., the right to make decisions for self and child) and *opposing them* in their attempts to retain or regain the ability to make decisions for themselves and their children. Parents' accounts identified system providers *disciplining* them like children and constantly

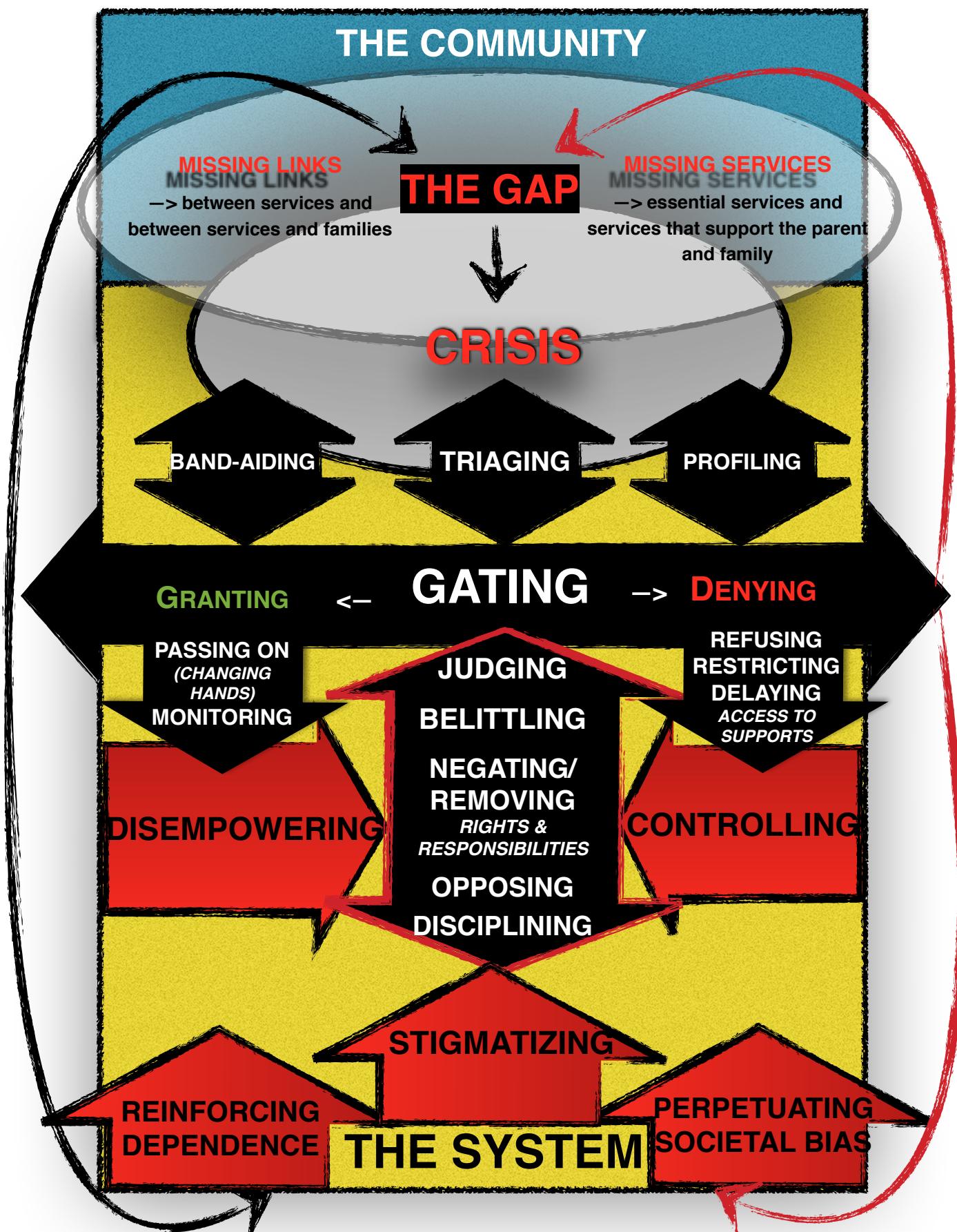


Figure 2: "THE SYSTEM"

looking for perceived mistakes. All parents identified the system as enforcing punitive measures for what it regarded as non-compliance with demands and expectations. Parents' accounts highlighted these as responses especially typical of The Ministry.

Majority of parents viewed system processes as profoundly *stigmatizing*. Many also faced what they considered to be discrimination from system providers against parents with MI and parents coming in contact with system services (especially with services of The Ministry). Parents experienced system providers as *judging* and *belittling* them, e.g., dismissing abilities and strengths; ignoring parents' assessments of their needs and requests for services; and typically viewing them as 'the problem'. Invariably, these actions and processes damaged the parents' self-worth, often compounding the challenges of MI and hindering recovery.

### **Seeing the big picture.**

There were undeniable benefits from entering "the system," such as gaining access to essential aid and services that could offer tangible benefits to the parent with MI and family. However, there were significant drawbacks that all but outweighed these benefits.

*Gating* access to services — especially *restricting, denying, or cutting off access to essential services* once the parent was 'out' of the system — had a pronounced impact on the parent and family as well as on the services' ability to provide meaningful support. *Gating access* increased the risk of a mental illness 'break' or family crisis and encouraged entering the system through emergency services. Crisis compromised the parents' ability to utilize services and delayed their recovery. Consequently, some parents saw the system's restrictions on access as weakening the ability of services to produce lasting benefits and as contributing to parents being

“caught” in the system’s ‘revolving door’. Many questioned the logic of a social system that reinforced dependence and one parent labeled such a system as “non-sustainable”.

Parents’ accounts underlined the system’s missing focus on prevention and supporting recovery. This was evident in the lack of availability and accessibility of certain recovery supports, such as safe affordable family housing and continued access to CA services. Many parents spoke of the difficulty of getting ahead of the next challenge and of moving forward, towards a desired future.

Most parents made the direct link between the system’s failure to meet needs and the ‘common knowledge’ of the system being underfunded and constantly cutting services. However, one parent questioned whether the system was marketing an image of being ‘underfunded’ as a public excuse for negligence. Counter to this image, some parents found a relative wealth of services once they were ‘in’ the system. However, availability did not seem to translate into ability to respond to needs. These experiences prompted some parents to question how system services were being managed.

A few parents criticized what they saw as the lack of accountability of the system to the public. Many parents felt that they had no recourse for the wrongful actions they experienced. One parent identified a lack of transparent, impartial, easily accessible complaints process. This further reinforced the parents’ perception of the system as working for itself, rather than for the best interests of the parent and family.

Parents also described system providers’ apparent lack of awareness of available resources (including ‘next door’ services) and consequent inability to offer information and referrals. This mirrored the parents’ experiences in the community. Some parents identified this as the

result of poor coordination of system services, i.e., a lack of a cohesive, integrated services continuum.

Some parents saw the neglected focus on prevention and service delivery as a direct consequence of the system perpetually responding to crisis. Parents questioned system providers' training as targeted towards crisis-response and lacking in other processes and practices (e.g., mental health assessment and support). Others implicated system providers' working conditions — crisis-driven and demanding — in providers' inability to facilitate a pre-emptive response.

Some parents questioned whether *triaging* had replaced comprehensive assessment. Parents talked about providers doing 'quick and dirty' assessments, as opposed to taking the time to listen and identify needs. All parents saw the system responding only to risks and problems. This prompted some parents to question assessment practices as biased or based on outdated perspectives and practice frameworks.

For all parents with MI, the experience of the system was punctuated by enduring stigma and what many saw as systemic discrimination against parents with MI and parents who must rely on government services. Parents identified system processes as both directly *stigmatizing* and as encouraging providers' bias, e.g., viewing the parent as a 'file' to be managed and passed on.

Many parents rebuked the system and system providers for *perpetuating societal bias* and discrimination. The parents' lived experiences reinforced their perception of the system as *misdirecting the public*: drawing attention away from the numerous problems, deeply ingrained within system operations by reinforcing the view of the parent as 'the problem'. A few participants directly implicated the system in perpetuating societal bias as a means of continuing operations

without being held accountable to the obvious gaps between the system's mandates and outcomes.

The power of government agencies and their representatives (including CAs) to irreversibly affect the lives of parents and families was highlighted in all parents' accounts of their experiences with parenting services. For many parents the system was a mechanism of control and marginalization: a "gear in the larger machine," maintaining the classist divide and oppression of the poor, the ill, and the disabled.

### **Responding — Not giving up.**

For many parents the reality of being part of the process of accessing system services meant an exacerbation of challenges related to dealing with MI. It meant being constantly reminded of the loss of certain abilities or of the self prior to illness. Many parents continued to grieve this loss, even after having made significant recovery gains. Those who experienced the (temporary) removal of parenting rights and separation from their children were profoundly shaken by these events. The trauma of this experience was evident in their accounts — even years after — as was the fear of re-experiencing such loss.

Many parents spoke of feeling stuck: locked into a degenerative cycle by illness, but especially by the lack of resources to maintain recovery gains. Some identified being unable to provide for their families as a personal failure and being dependent on others as demoralizing. Some spoke of feeling like 'a burden' on friends and family and of contemplating ending the suffering by suicide.

This was the emotional reality for most of the parents dealing with MI — on top of the struggles of parenting and, for many, poverty, single parenthood, and multiple other stressors.

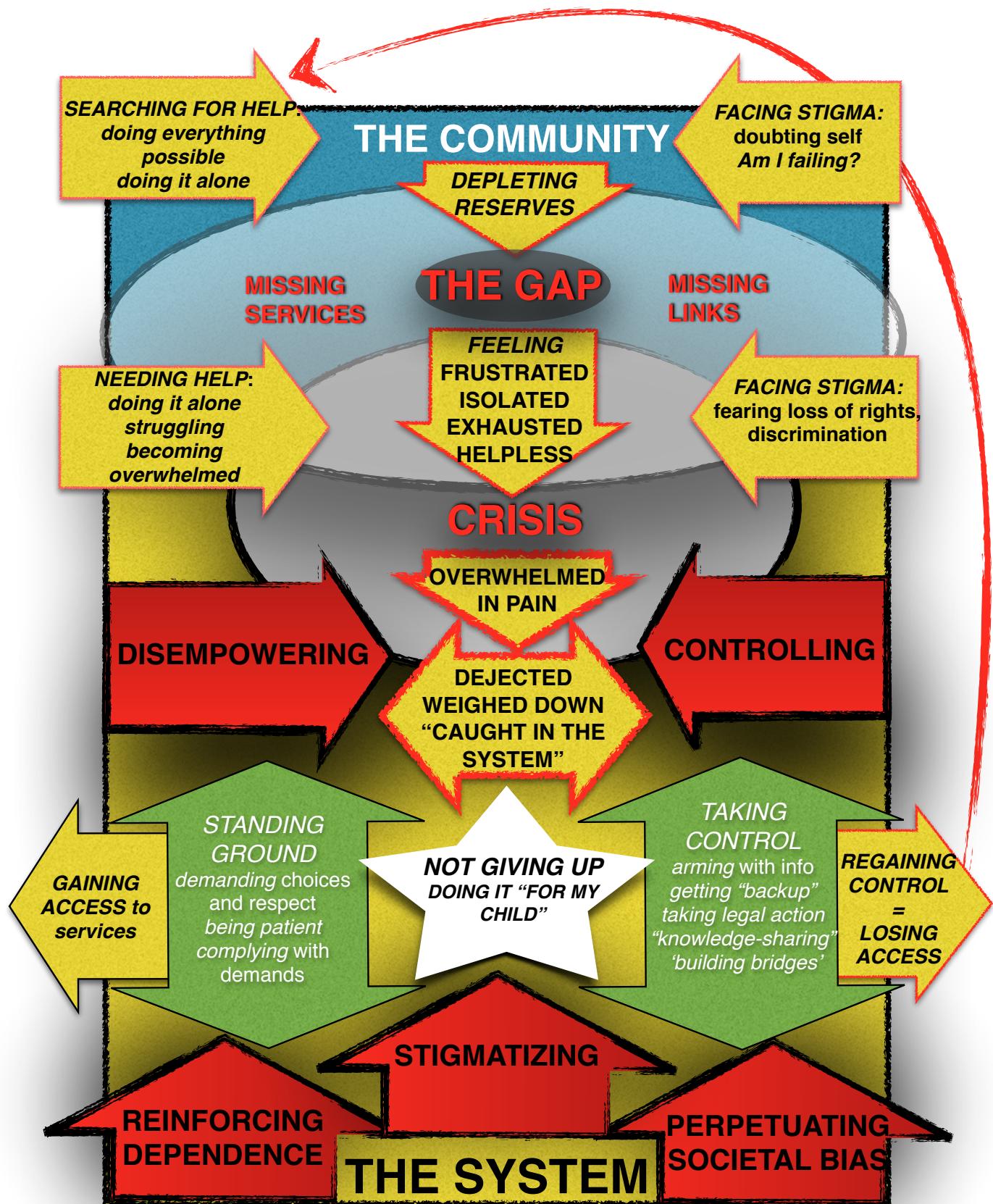


Figure 3: PARENT RESPONSE

Incredibly, in the face of these challenges, all parents spoke of the importance of *not giving up* and of the gains that come with persevering. In the context of the system that reduced people to ‘files’, invalidated rights, punished, controlled, and systematically stigmatized and disempowered, *not giving up* took every ounce of strength and will.

*Not giving up* meant making ends meet on a daily basis and fighting the pull of the illness into despondency and isolation. Many did this by helping others: volunteering in their community; helping neighbours and even strangers.

Parents talked about *standing their ground: demanding choices and respect*. For some this meant insisting that system providers acknowledge their competence and strengths. For others this meant persistently repeating requests and restating needs. Many felt that these actions were necessary to gain access to system services.

Some parents were able to muster the strength and resources to attempt *taking back control: ‘arming’ with information* (by accessing any and all available sources) and *getting “back-up”* from professional advocates. Parents who worked with advocates (exclusively from COs) felt that this always changed the dynamic of the parent-provider relationship. They saw system providers as being opposed to this change, as if they were threatened by the parent gaining strength and voice. Parents also talked about taking control through legal action. Those that did, felt that this was their only recourse to a fair resolution to disagreements with system providers, especially regarding the care of their children.

Not all parents were fortunate enough to acquire the resources to directly challenge the system. Some felt that active resistance or disagreement was interpreted as non-compliance by system providers and could compromise their chances of regaining parenting rights and/or ac-

cessing services. Consequently, parents spoke of the importance of showing cooperation and ‘doing what they ask’. For these parents, *standing ground* meant *being patient* and *complying* with demands.

All parents actively distributed information to peers and providers. Through this “*knowledge-sharing*” parents were helping peers to respond to the system, to be better prepared to take back control, if the opportunity arose. In these ways parents were also contributing to a supportive community, *‘building bridges’* across the small ‘islands’ of isolated families struggling to keep afloat.

All parents identified their motivation for *not giving up* as *doing it “for my child”*. Many said, that if it wasn’t for their children, they wouldn’t keep doing this. Parents clearly foresaw the impact of ‘giving up’ on their children’s future and did everything in their power to persevere.

*Not giving up* also meant *holding on to hope* for a better future for their children and family. Sharing that sense of hope was just as important. One parent summed up the sentiments of others: “It’s worth fighting for.”

## **Supporting parents**

### **Supportive Context.**

Participants identified providers and organizations that engaged in supportive processes. These were seen as extra-ordinary individuals.

Contracted agencies (CAs) and other community organizations (COs) featured prominently in the parents’ accounts of supports. CAs’ strength and weakness was their tie to the system. While allowing CAs to provide critical services, the system also placed them in a conflict of interest — by mandating that they both support and inform on the parent and family. Some par-

ents viewed system contracts as limiting CAs effectiveness, including making it difficult for CAs to advocate for the parents and families in the context of system service. Conversely, COs' strength was in *advocating* for the parents. Their weakness was the inability to offer the same level of services as the CAs. Peer support groups and networks also played a strong role in providing information to parents and in connecting parents to a supportive community.

Government (or "system") services had differentiated supportive roles (e.g., BC Housing only provided housing assistance). All were seen as exclusively focused on *meeting basic needs* of the family, but (at best) only partially fulfilling their respective roles. Parents identified "The Ministry's" sole supportive role as connecting parents to CA services.

The role of legal services was in *advocating* for the parent in the context of Family Court (FC). Lack of accessibility of pro-bono legal services was seen as their main weakness. While all participants (irrespective of whether they were working) were unable to afford lawyer services, most were categorized as ineligible for Legal Aid due to exceeding the income cutoff (i.e., making too much to be granted access).

Individual schools were regarded as offering strong supports for children; and some school staff were seen as *collaborating* with parents. One participant also spoke highly of a community church organization that offered practical supports to the families (e.g., a high quality food and clothing bank) as well as emotional support (e.g., peer support groups). However, this appeared to be a singular experience.

## **Supportive Processes.**

Exceptional individuals and services engaged in the processes of *supporting recovery, strengthening, collaborating, working relationally and ethically, and doing due diligence*. These individuals and processes were highly valued by all parents.

The process of *supporting recovery*, especially *meeting basic needs and maintaining connections* to families, was viewed by all participants as invaluable to the well-being of the parent and family. Connections bridged the service gaps and were critical to building and maintaining supportive communities.

The process of *strengthening: advocating and guiding* was closely linked with *supporting recovery* in the parents' accounts. *Advocating* was a key support to parents in the system, allowing them to retain a level of control over an otherwise 'runaway' process. *Guiding* often took the form of *providing accurate information* and *connecting to services*. Some parents likened this to the processes of motivating and empowering.

*Collaborating* was connected with both strengthening and supporting recovery. Parents spoke of a few providers that *treated them with respect* and *valued their contributions*. Collaborating involved *setting mutual goals* and *working together* to achieve them. Negotiating roles was clearly an important process in working together. Parents appreciated providers who did not expect them to do the providers' job (e.g., locating resources) and who did not interfere in the parents' duties (e.g., making decisions for the child and family). Community providers (from CAs and COs) were most commonly viewed as partners.

*Working relationally* was another significant process. *Giving time* meant caring and having a genuine intention to help. *Empathizing*: relating and recognizing both suffering and

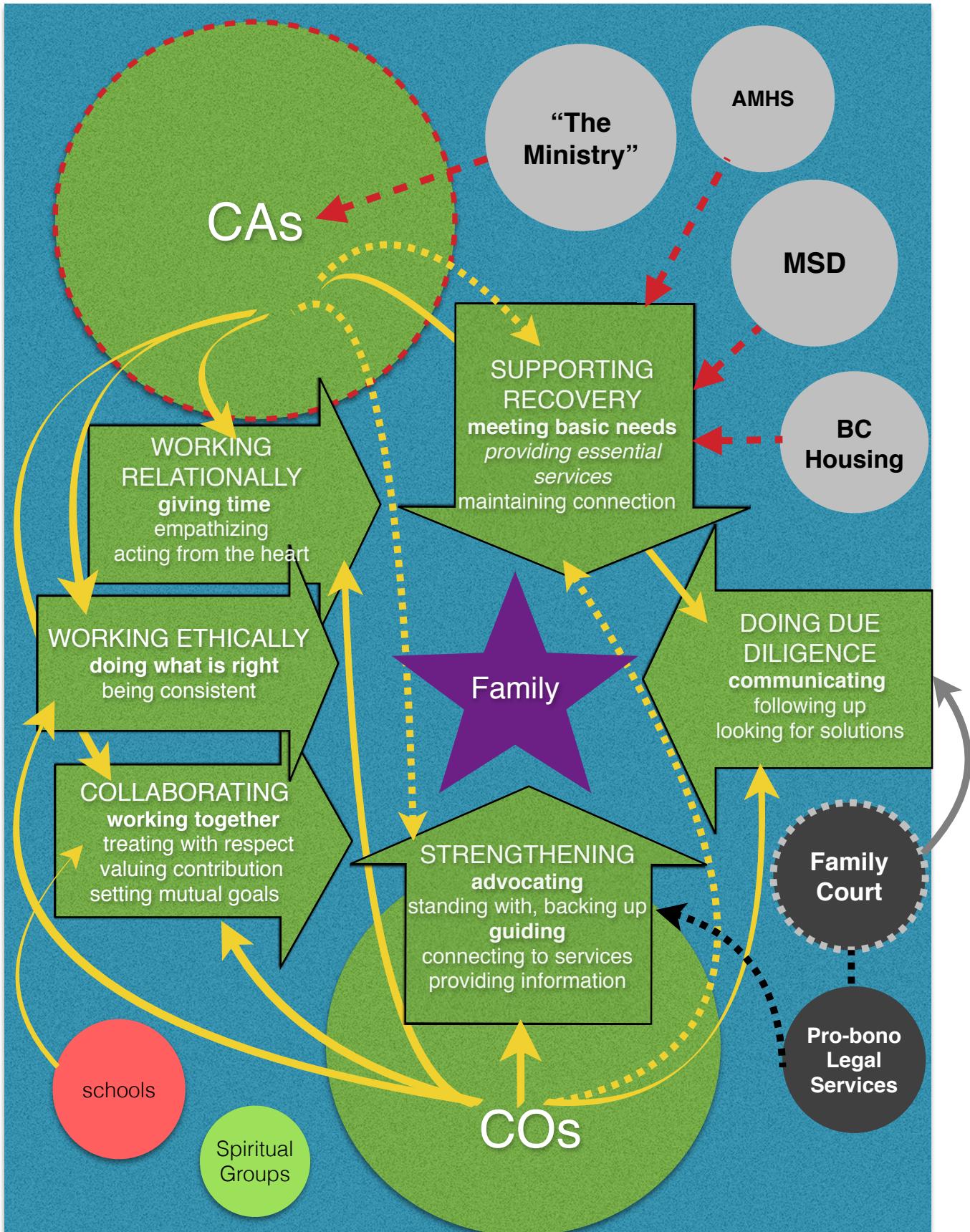


Figure 4: SUPPORTIVE CONTEXT

strength was also highly valued. Some parents spoke passionately about providers *acting from the heart*: showing compassion and kindness without expecting anything in return.

*Working ethically* had significant consequences for providers. Parents commented on what they perceived to be especially challenging for some providers: reconciling *doing what is morally right* with working within (or with) the system. Parents spoke of extraordinary providers who risked their professional integrity (and their jobs) by choosing to do what they felt was right over ‘going by the book’.

Finally, parents talked about providers *doing due diligence: communicating, following up, searching for solutions*. These were seen as basic supportive processes, without which even the best intentions meant little.

Overall, the parents’ accounts identified a services context that was lacking an integrated, cohesive ‘system’ of supports. Without this, exceptional individuals were like threads of a broken web, unable to catch the family when it was falling or to fully support it in getting back up.

### **Tearing down walls - Building bridges**

From ‘tearing down’ the system to building relationships — parents made several recommendations for addressing what all saw as significant ‘flaws’ across service domains. Some parents spoke of abolishing the current “system” of government services and building a new ‘community’ of services based on the principles of social equality and justice. Parents’s accounts highlighted the need for replacing the current fragmented system with an integrated, coordinated system of supports that could offer a continuum of services to the family.

Barring a complete overhaul, parents identified an urgent need to identify and address systemic bias, i.e., protocols and practices that discriminate against parents with MI and parents

coming in contact with the system. This was a high-priority recommendation for “The Ministry” (MCFD) and MSD. Additionally, many parents called for public accountability from government agencies for outcomes that clearly did not match publicly stated mandates and goals, such as ‘working for the best interests of the child and family’ or ‘eliminating homelessness’.

Parents also spoke of ‘changing the lens’ of the current system. Parents strongly urged system providers to expand their focus on prevention and supporting recovery, including: increasing availability and access to safe, affordable, family housing; increasing government income assistance to meet the basic needs of the family (e.g., food, hygiene, clothing, and recreational opportunities for the child); and eliminating barriers to disability assistance and other essential services, such as respite support. Many spoke of the need for ‘publicizing’ mental health: making mental health services publicly visible and accessible and increasing public awareness of MI and appropriate supports.

Parents spoke of the need for system services to standardize their approach and align with collaborative frameworks and “best practices” for working with families affected by MI. Many parents’ accounts highlighted the need for system providers to acquire training (including cross-disciplinary training) and ongoing upgrading of skills related to working with parents with MI and their families.

Parents also identified the importance of critically examining the system’s relationship to community services, including evaluating the impact of the system restricting access to CAs. The majority felt strongly that lifting restrictions on access to all community-based services and enabling the community to provide essential services would stop the cycle of crises for the family and facilitate recovery. Strengthening community services was viewed by participants as impera-

tive to building a supportive community for parents with MI and families. Overall, participants stressed the need for the parent services context to increase its capacity to serve parents with MI.

Within the community domain, parents identified a clear need for improving access to accurate information about available services, including increasing capacity of services to offer referrals. Many viewed improvement as an outcome of increased coordination within and between community and system services. This was highlighted by the recommendation to facilitate the roles of hospitals, schools, and social work services as ‘information hubs’.

In addition to the importance of building relationships across service domains, parents identified the importance of the parent-provider relationship. Parents encouraged providers to give time to the parents and families and to get to know *them*, not just their files or profiles. Some suggested that understanding the family dynamics and culture (including relationships with extended family members) would increase the relevance of supports. Parents also implored providers not to judge, ridicule, or act out personal bias. They appealed to providers’ compassion and asked them to remember the reasons for becoming helpers. Many parents saw the need for service providers to “do more” to combat the stigma against parents with MI, beginning with the parent-provider relationship.

Parents’s accounts highlighted the importance of eliciting the perspectives of parents with MI to understanding the impact of parenting services on the parent and family and to identifying services’ failures and successes. As one participant offered, “The system is broken for all,” but parents with MI have a unique perspective on “the system” from the intersection of the roles of ‘parent,’ ‘person with MI,’ ‘person with disability status,’ ’service user,’ (often) ‘parent of a child with special needs’, among others. Many participants spoke of the lack of engagement of

providers (either in formal evaluations or informal discussions) with parents with MI regarding their experiences of services and viewed this as responsible for the lack of movement towards necessary changes. All parents expressed the value of having their voices heard by providers, academics and the public and stated this as their primary motivation for contributing to this study.

### **Summary of recommendations.**

Key actions identified by study participants as facilitative of the ability of parenting services — community and government — to support parents with MI and their families are as follows:

1. *Align the design and delivery of mental health and social services with public health and social justice perspectives and approaches*
  - Focus on preventive and recovery services
  - Provide equitable, public access to all essential services
  - Ensure that essential services meet the basic needs of the parent and family (e.g., safe, affordable housing; food security; respite; psychiatric supports)
2. *Critically examine the parent services context for systemic discriminatory and inappropriate practices and eliminate these*
  - Establish an impartial body to oversee system services delivery and provide a safe means for parents to voice concerns
3. *Actively target stigma against parents with MI in society as well as within the professional community*
  - Promote public awareness of MI and supports
  - Increase the visibility of mental health services in the community
  - Provide ongoing training in mental health support for service providers

*4. Increase capacity of parenting services to offer a continuum of services to the parent with MI and family*

- Increase ‘on the ground’ collaboration within and between service domains (community and government)
- Increase availability and accessibility of community-based services

*Including parents as partners in these activities — ensuring that their voices are heard and their recommendations reflected in the service plans — was considered by all participants as imperative to creating a service ‘community’ capable of providing responsive services and facilitating recovery and wellness for the parents with MI and their families.*

Participants unanimously expressed their desire to help service providers understand their experiences and through this process, be empowered to facilitate change. Participants also expressed the expectation that changes would not be easily made. Many encouraged providers to “do more” and to “walk with” parents in their efforts.

### **Disseminating findings**

These findings are expected to be disseminated via ‘top down’ academic channels, as well as through ‘ground up’ community service settings and peer networks.

The study will be presented to the thesis committee and an external examiner at the University of Victoria. Following thesis approval, it is expected that the findings will be presented in one or more academic conferences within the first two years of research completion and may be published in one or more academic journals.

The final report on findings (Appendix F) was provided to the partnering agency representative in October 2015, to be distributed to the agency and its community partners. The partnering agency’s stated use of findings is to support program development aimed at the needs of

the local community of parents with MI and their families (agency representative, personal communication, January 31, 2014). There may also be opportunities to present the findings will be presented to the partnering agency (at various branches) and other local service agencies. The monthly meetings of the collaborative roundtable of local service providers, hosted by the partnering agency, may be one setting for this to occur (agency representative, personal communication, January 31, 2014). Direct program staff from the partnering agency will not be invited to presentations on findings to maximize participant anonymity.

Additionally, the final report was distributed to six out of eight participants between October and November 2015. Two participants could not be reached at that time; however the partnering agency representative has contact with these participants on a semi-regular basis, hence, there may be an opportunity to reach these participants in the future. All participants are invited to distribute the information to their peers and others as they see fit.

The ability to disseminate findings to the community of local service providers, study participants and their peers is considered vital to fulfilling the study's usefulness. Hence, the distribution of finding will be ongoing, based on interest from the service community. However, careful consideration will be given to how information is distributed (i.e., what information to whom) to minimizing potential harm to participants. All identifying information, including the name of the partnering agency and the agency representative, has been excluded from reports (and the final version of the thesis that will be published on the university site). No identifying information will appear in the future presentations of findings. Additionally, all precautions will be taken to ensure that participants are not inadvertently identified by the information presented. For example, audiences for presentations on findings may be restricted. This follows the sugges-

tion by Ahern (2012), who found that dissemination of findings from research conducted within a small community *to that community* increased the risk of participants being identified indirectly, for example, by the research topic or the information presented.

### **Intent for findings**

The findings of this study are preliminary, or in the words of one participant, “the tip of the iceberg”. Nonetheless, these findings present starting points for discussions about services for parents with MI. The finding are also intended to stimulate interest in future research, especially research that engages parents with MI as partners in the process of generating evidence to support the implementation of needed changes to the context of parenting services for parents with MI and their families.

## Chapter VI: Discussion

### Introduction

The key findings of this small-scale exploratory study are discussed in this chapter. The findings provide a glimpse into the experience of parents with mental illness (MI) of parenting services *from their perspective*. They underscore the influence of the service context — embedded within socioeconomic and political structures — on the process of the parents' engagement with services (i.e., whether and how parents accomplished and sustained access to services) and on the outcome of this engagement (i.e., whether and how services met the needs of the parent and family). The impact of the services context on the parent and family, especially as contributing to (or being unable to prevent) the intersection of the personal mental health (MH) crisis with that of family crisis, highlights a distinctiveness of the experience of parents with MI of parenting services. The findings clearly point to the need for a 'seismic shift' (Health Council Canada, 2010) in public health, mental health, and social services policy and practice, as well as to the imperative of engaging parents with MI as partners in that shift.

The discussion is presented in three sections. It begins with a sketch of the context of parenting services, as described by the study participants and as situated within the social services and mental health services (MHS) literature. In this section the characteristics of the services context and its influence on the process of parental engagement with services are discussed. The next section considers the service experience of participants in relation to the process of marginalization. A gendered perspective is offered to further situate the findings within a historic continuum of discrimination and to suggest a link between service providers' and service participants' experience. This section concludes with attention to resistance as response to domi-

nant structures and processes of parenting services. Recommendations of the study participants regarding necessary changes, and how these can be achieved, are taken up in the last section.

It is acknowledged that limitations of the study (discussed in Chapter IV) limit the strength and generalizability of findings. The study's aim was to begin the exploration of the landscape of parenting services for parents with MI and their families, *from the parents' perspective*. This sketch is intended to be used as a guideline for future investigations and discussions. Research is strongly encouraged to define the parameters and the components of the context of 'parenting services,' as well as explicate the relationships within this context, such as those between systems, between systems and community services, and between 'parenting services' and affiliates (e.g., the legal system). Additionally, in-depth investigations of the many aspects of the experience of parents with MI of this context — for example, how parents respond to service-related barriers — are necessary to fill in the gaps and answer the numerous questions that remain. The study findings highlight the importance of engaging with parents with MI and their families — with the *people with lived experience* of service policy and practice — as partners in future research. Research that fails to do this risks overlooking critical elements — or worse, perpetuating the status quo of silencing the voices of these parents and families.

### **Sketching the context of parenting services**

The following section outlines the parameters of the context of parenting services, based on the study findings and situates this context within the MH and social services literature.

### **The context of parenting services for parents with MI.**

Participants described a broad spectrum of parenting services, reflecting the multi-faceted experience of parenting with MI (Benbow, Forchuk, & Ray, 2011; Nicholson et al., 2001). Participants identified two service domains within this context: services provided by government agencies — collectively referred to as “the system” — and services offered by community organizations. These were distinguished by access structures and approaches to practice.

“The system” was differentiated by its practice of gating access to essential services: income and housing subsidy; respite; and psychiatric and therapeutic services for the parent and child. System services were the most difficult to access and placed the most administrative demands on the parent. Community services were defined by greater flexibility in access and a more collaborative approach to practice.

#### ***Community.***

Government contracted agencies (CAs) stood out from other community organizations (COs) in participants’ accounts due to their contractual ties. While contracts enabled CAs (through program funding) to offer essential services to the family (e.g., counselling for the parent and child), they also appeared to extensively restrict CAs’ operations. Access to most CA services could only be accomplished and maintained through the system; that is, through an open file with a government agency.

In contrast, COs provided least-barrier access. However, study participants noted a significant difference between services *with* government funding (mainly CAs) and services without, with respect to the services’ ability to offer programs and respond to needs. The one exceptional

strength of COs was their ability to provide advocacy services to the parent in relation to the system. These services were highly valued.

Overall, the system's impact on the community services sector was more strongly emphasized by participants than individual services. In particular, the allocation of government funding (that enabled some and limited others) and restrictions on access to contracted agencies received the most attention from study participants. In contrast, the service literature appears to be silent on these issues.

### ***Systems.***

Two “systems” were identified as key players in the context of parenting services for parents with MI. The system of *social ‘welfare,’* composed of the Ministry of Social Development and Social Innovation (MSD) and BC Housing, provided income assistance and housing subsidy. These resources were identified by participants as *critical* to parental and family well-being. The system of *child ‘welfare,’* embodied by the Ministry of Children and Family Development (MCFD) or “The Ministry,” encompassed Child Protective Services (CPS), Child Mental Health Services (CMHS), and respite services, as well as provided access to counselling and education-based supports for the parents. Together, these systems had a monopoly on the majority of essential services for parents and families affected by MI.

The social ‘welfare’ system does not appear in the discussion of service engagement of families affected by MI, in the MHS literature. Socioeconomic deprivation is acknowledged as a barrier to services (Franks, Henwood, & Bowden, 2007; Government of Canada, 2006; Mensah & Kiernan, 2010; Murdoch & Hall, 2002; Nicholson, Albert, Gershenson, Williams, & Biebel, 2008; van der Linden, Drukker, Gunther, Feron, & van Os, 2003). However, the emphasis seems

to be on personal factors of service use, such as symptoms of illness (Boyd, Diamond, & Bourjolly, 2006; Franks et al., 2007; Weissman et al., 2006) and motivation (Thomas & Kalucy, 2003). There is recognition of the intersecting demands of parenting and managing MI (Bassett, Lampe, & Lloyd, 1999; Boyd et al., 2006; Franks et al., 2007; Nicholson, Sweeney, & Geller, 1998; Swartz et al., 2006); however, these demands are not situated in the context of social ‘welfare’ policy and practice. Conversely, the study findings point to this system as a key factor of parental engagement with parenting services.

Charity services (religious and secular) were identified as a branch of the social ‘welfare’ system. While these services were appreciated, they were far from sufficient to meet the family’s needs. Participants viewed the prominence of charity services to be reflective of deficiencies in the social ‘welfare’ systems. This assessment can also be found in the social services literature (e.g., Food Banks Canada, 2014; Gurstein et al., 2008; Klein et al., 2008a).

The system of child ‘welfare,’ in its incarnations as CPS and as CMHS, has received attention in the MHS literature in relation to parental engagement with services. CPS has been identified as responding mainly to parental deficits and failures (Ackerson, 2003b; Bassett et al., 1999; Reupert & Maybery, 2007) and as lacking the skill-base to offer effective parenting or family-centred supports (Marsh, 2009; Reupert & Maybery, 2007). Participants also identified CPS as reactive, punitive, and profoundly stigmatizing. The benefit of coming in contact with CPS was potentially gaining access to CMHS, respite, and counselling for the parent and family. Notably, though CMHS do not require that the parent or child have an open CPS file, the parents viewed the two branches of “The Ministry” as intimately connected, viewing access to one as inevitably leading to contact with the other. The study findings were unclear on whether the ben-

efits of contact outweighed the risks, especially the risk of losing parental rights and responsibilities.

CMHS services were defined in the MHS literature as highly specialized (to the needs of the child) and therefore generally less focused on the needs of the parent and family (Ackerson, 2003b; Bassett et al., 1999; Reupert & Maybery, 2007). Participants affirmed that CMHS provided quality services for their children, however, it is unclear how (or how well) these services supported the parents. Evaluations of these services' parenting supports for parents with MI appear to be missing from the CMHS literature.

Adult psychiatric/mental health services (AMHS) were identified by study participants as a necessary component of "the system" of parenting services. These were described as providing a high standard of care for (adult) *individual* psychiatric needs. The MHS literature reflects this specialization. Adult services do not routinely recognize the parenting role (Maybery & Reupert, 2009; Nicholson, Biebel, Katz-Leavy, & Williams, 2004), and adult service providers have identified a lack of skill in the area of parenting and family-centred intervention (Alakus, Conwell, Gilbert, Buist, & Castle, 2007; Boyd et al., 2006; Maybery & Reupert, 2009).

Notably, many participants also accessed counselling services, in addition to AMHS. Counselling for the parent and child was mainly accessed through "The Ministry" (via contracted agencies), as private or for-fee services were unaffordable for low-income families. Access to these MHS was most frequently accomplished post-crisis, which could be reflective of these services' lack of preventive focus. Further, the study findings indicate a gap between the recognition in the MHS literature that prevention is the cornerstone of MHS (Kirby & Keon, 2006; Mental

Health Commission of Canada [MHCC], 2012; World Health Organization [WHO], 2013) and practice.

The child education system, including alternative education programs and school counselling services, was also mentioned by participants as relevant to the parenting role. Child education programs were described as generally accessible, effective and collaborative. In the MHS literature, the child education system was identified as a point of first contact for parents seeking MHS for the family (Burnett-Zeigler & Lyons, 2009; Burnett-Zeigler et al., 2012). As well, the systems' ability to 'bridge the gap' between families and MH supports by providing MH assessment, intervention and referral has been recognized and supported (Manning, 2009; MHCC, 2013b). The study findings provide evidence for strengthening the capacity of this system to act as a link between families and MH supports.

The legal system, represented by legal aid services (provided by the Legal Services Society in BC) and family court (FC), were also mentioned as highly relevant parenting supports. Although these services were generally identified as effective, participants expressed great concern with the system's accessibility to low-income families. Legal aid services have highly restrictive financial and issue-specific qualifiers (Brewin & Stephens, 2004; Morrow, Frischmuth, & Johnson, 2006). For a few study participants, no legal aid meant increased risk of losing access or compromised access to their children, as well as delayed family reunification.

While the legal system represented an important component of parenting services, participants typically described it as a 'different animal,' with a set of rules and standards that appeared distinct from the parenting services systems. Hence, it may best be viewed as a close affiliate of the parenting services context.

The juxtaposing of study findings to literature highlights strengths and weaknesses within the understanding of the *context of parenting services for parents with MI* and identifies areas for future research. The next section discusses characteristics of the services context and its influence on the process of parental engagement with services.

### **Fragmented, restrictive, reactive service response.**

The study findings point to a disjointed spectrum of supports and a restrictive, reactive context that is failing to respond to the needs of parents with MI and their families.

#### *A fragmented spectrum.*

The lack of a support *network* — expressed by participants as “The Gap” — was evident in participants’ descriptions of the community services sector. Participants described community services (especially MHS) as invisible, having insufficient reach, as well as often lacking service information, which impacted their ability to offer relevant referrals. The relative invisibility of MHS (in comparison to other health services, for example) has been identified as a barrier to service access for parents with MI (Ackerson, 2003a; Bassett, Lampe, & Lloyd, 1999; Lees et al., 2002) and parents seeking CMHS (Boydell et al., 2006; Compton, Kaslow, & Walker, 2004; Sayal et al., 2010). It has also been shown to correlate with providers’ lack of knowledge about available services (Alakus, Conwell, Gilbert, Buist, & Castle, 2007; Maybery & Reupert, 2009).

This “Gap” was present within and between community and system service domains. System services were described as operating independently of each other and of the community. The Health Council of Canada (2010) described this mode of working of government ministries as being at the root of the failure of the social and health systems to offer accessible and com-

hensive services. Similar assertions where made by Kirby and Keon (2006) in their influential report on the state of CMHS in Canada, *Out of the Shadows at Last*.

Overall, the picture presented is that of a fragmented services spectrum. The general lack of cohesion in services provision is recognized in the MHS literature, in that families are having to face an unnecessarily complex process of access, often leading to delay in services (Kirby & Keon, 2006; Representative of Children and Youth [RCY], 2014b; Reid et al., 2006; Sayal et al., 2010; Shanley, Reid, & Evans, 2008) or having to access multiple services to meet developing needs (Darlington, Feeney, & Rixon, 2005; Kirby & Keon, 2006; MHCC, 2012; Morrow, Frischmuth, & Johnson, 2006; RCY, 2014b). Participants' accounts emphasized the consequences of searching for supports within an inefficient, tattered support 'network' as draining parents' resources, exacerbating challenges of parenting with MI, and directing the parents' service access trajectory, leading them into the system (Figure 1).

### ***Restrictive access and inadequate response.***

The policies and processes of "the system" — in particular, the social and child 'welfare' systems — restricted access to essential resources, compounding the impacts of an ineffective support network on the parent and family.

The study participants' assertion that the social 'welfare' system is failing to provide sufficient aid at critical times is affirmed by investigators of BC's 'welfare' policy and practice (e.g., Klein et al., 2008a, 2008b; Tweedle, Battle, & Torjman, 2013; Wallace, Klein, & Reitsma-Street, 2006). Many commentators have described these policies as unreasonable and inappropriate (FBC, 2014; Klein et al., 2008a, 2008b; Office of the Ombudsperson, 2009; Wallace et al., 2006). Similarly, the income subsidy has been identified as grossly inadequate (FBC, 2014;

Klein et al., 2008a, 2008b; Tweedle et al., 2013; Wallace et al., 2006). For example, BC disability assistance rates place a family far below (on average 40% below) the poverty line (Tweedle et al., 2013), creating food insecurity (FBC, 2014) and serious risk of family homelessness (Klein et al., 2008a, 2008b; Metro Vancouver [MV], 2015; Wallace et al., 2006).

Subsidized housing — identified as a *primary* resource by study participants — was described in the study as difficult to access due to lack of available options. Data on the state of social housing (see BC Non-Profit Housing Association [BCNPHA], 2013; MV, 2015) confirms participants' perceptions. BC Housing wait list has risen 30% in the last 5 years, to over 9,670, and delays in access to subsidized housing are expected to worsen (BCNPHA, 2013; MV, 2015).

Further, the study findings highlight the relationship between MHS and CPS as another barrier to essential services for parents with MI and their families. For example, the policy of mandatory reporting by MHS providers to CPS of any potential risks to the child (Nicholson, et al., 2001) — and the identification of parental MI as such a risk (Bassani, Padoin, & Vendhuizen, 2008; Marsh, 2009; Murdoch & Hall, 2002) — resulted in some parents avoiding accessing MHS. Parents expressed the perception that contact with CPS would lead to providers negating or removing their parental rights. Though less than 10% of The Ministry's investigations between 1998 and 2008 resulted in removal (Trocme et al., 2010), parents with MI (over 90% mothers) were at greater risk of losing custody (Min Park, Solomon, & Mandell, 2006; Trocme et al., 2010) and had longer periods of contact with The Ministry overall (Westad & McConnell, 2012). The potential for custody loss — and the fear of that potential — has been identified as precluding parents from accessing MHS (Ackerson, 2003a; Nicholson, Sweeney, & Geller, 1998;

Nicholson et al., 2001). Hence, the relationship between MHS and CPS has been noted as a potential factor in a family's functional decline (Ackerson, 2003b; Nicholson et al., 2001).

***Cyclical, crisis-driven pattern of access and response.***

The study findings indicate that a lack of preventive service response significantly exacerbated parental and family challenges, precipitating crisis and increasing the likelihood of contact with hospital emergency and CPS. Nicholson and colleagues (2001) note a similar, crisis-driven pattern of service access as a consequence of a failure of system supports to recognize and address urgent needs.

Participants noted that crisis was the point at which services intersected. Getting 'in' through emergency services resulted in contact with multiple services at once — a stark contrast to the isolation from supports (i.e., "The Gap") that parents experienced in the community. One participant vividly described this pattern of service response: "*It always comes from a place of pain.*"

Getting through the system's gate did not guarantee sustained recovery supports. Failure to support recovery has been identified as a result of policies that neglect to take into account the episodic nature of MI (Trainor, Pomeroy, & Pape, 2004). For study participants, recovery gains were frequently undermined by premature suspension of services, which meant that the parent and family were once more on their own — back in "The Gap". This pattern of 'access through pain' and minimal, unsustained supports generated a cycle of crises and service dependence for the parents with MI and their families.

## **Conclusion.**

The study findings indicate that the context of parenting services has a far-reaching impact on parents with MI and their families. This context affects whether and how parents come in contact with individual services and the overall pattern of service utilization. In particular, the policies and practices of social and child ‘welfare’ services appear to significantly influence the outcome of service engagement (e.g., how much support the parent received and for how long), especially impacting the process of parental recovery.

## **Experiencing “the system” of parenting services**

This section discusses the process of parental engagement with system services as a process of manufacturing marginalization of parents with MI and their families. A gendered perspective is then utilized to bring this process into focus as part of a historic continuum of discrimination. The potential similarity between participants’ and providers’ experiences of and responses to the dominant structures and processes of system services is highlighted.

### **Parallel processes of manufacturing marginalization.**

A key study finding was that participants’ experiences of the system of parenting services were directly related to their experiences of marginalization within society. Participants’ accounts indicated a connection between the experiences of social and economic deprivation and excessive institutional control, and the experience of profound demoralization and powerlessness. This relationship has been described in the social services literature (Benbow, Forchuk, & Ray, 2011; Goldberg & Long, 2003; Gurstein, et al., 2008; Jategaonkar & Ponic, 2010; Klein et al., 2008a, 2008b; Mikkonen & Raphael, 2010; Sieppert, te Linde, & Rutherford, 2004; Trainor, Pomeroy & Pape, 2004; Tweddle, Battle, & Torjman, 2013; Wallace, Klein, & Reitsma-Street, 2006); and

in the consumer/survivor literature (Beresford & Wilson, 2002; Marsh, 2000). Participants further highlighted the processes of stigmatizing, discriminating, and silencing as characteristic of their experience of the system of parenting services. The outcome of these processes appeared to be a system aimed at controlling and disempowering parents with MI and their allies (e.g., advocates, community service providers).

### ***Stigmatizing.***

Stigma permeated the study participants' experience of parenting services. Participants described three kinds of stigma: stigma associated *with MI*, *with parenting with MI*, and *with coming in contact with child and social 'welfare' systems*. The stigma associated with MI has been nationally recognized as having significant influence on the lives of persons with MI (Kirby & Keon, 2006; Knaak & Patten, 2014; MHCC, 2013, 2012). In contrast, the stigma related to parenting with MI has only been mentioned in the MHS literature (Ackerson, 2003a; Mowbray, Oyserman, & Ross, 1995; Nicholson, Sweeney, & Geller, 1998) and in the MH system survivor/user literature (Marsh, 2000); it does not appear to be widely acknowledged. The shame in seeking services essential to survival of a family affected by parental MI (e.g., disability assistance, respite services) has yet to be recognized by the service literature.

Participants identified these stigmas as common and viewed the stigmatizing attitudes of service providers as reflective of those found in society. Participants' experience of "the system" was especially stigmatizing. Participants spoke of being judged by their challenges, blamed for the difficulties they and their families were experiencing and generally belittled by system providers. Study participants viewed stigma within society and within the services sector as both arising from and reinforcing systemic discrimination.

***Systemically discriminating.***

Participants' accounts outlined systemic discrimination in "the system's" policies and practices. Clear examples of systemic discrimination were: denying disability status (despite clear evidence), which restricted access to essential supports; negating or removing parental rights and responsibilities based on disability (versus being supported to maintain their ability to parent); and refusing or cutting off access to resources or services critical for survival.

These findings indicate that access to social goods (such as housing) and services is not provided fairly, nor are rights protected or upheld equally among all Canadians. These assertions are supported by the social services literature (First Call, 2014; FBC, 2014; Jategaonkar & Ponic, 2010; Klein et al., 2008b; Tweedle et al., 2013; Wallace et al., 2006), as well as by the health and public health services literature (Canadian Institute for Health Information [CIHI], & Statistics Canada, 2013; Health Council of Canada [HCC], 2010; Mikkonen & Raphael, 2010; National Collaborating Centre for Determinants of Health [NCCDH], 2011; Ontario Ministry of Health and Long-Term Care [OMH], 2012; Public Health Agency of Canada [PHAC], 2006).

***Silencing.***

The study findings further highlight the importance of advocacy services to accomplishing service access and assuring fairness in the process of contact with "the system". Moreover, participants spoke of advocacy services as allowing them to have a voice in the relationship with system providers.

Participants' accounts indicated that advocacy services were provided almost exclusively by non-contracted community organizations (COs). While appearing to be well-positioned to act as advocates for the parents and families in relation to the system, contracted agencies (CAs) did

not appear in this role. Community organizations' (and perhaps especially CAs') reliance on government funding appears to restrict their ability to raise issues related to government policy and practice (Sieppert, te Linde, & Rutherford, 2004).

Advocacy services increase access to essential services (Morrow, Frischmuth, & Johnson, 2006; Westad & McConnell, 2012) and aid in access to fair process by persons with disabilities, women and low-income families (Brewin & Stephens, 2004). Highlighting the importance of community advocacy services, participants spoke of finding no avenue in the system to express their concerns or address the wrongs they experienced. The systems' internal complaints processes were viewed as inherently biased and as potentially resulting in punitive measures against the parent and family, such as denying or restricting access to services.

External to the systems of parenting services, there are two provincially appointed advocacy bodies: the Office of the Representative for Children and Youth (RCY) (see Representative for Children and Youth [RCY] Web site, 2015) and the Office of the Ombudsperson (see Office of the Ombudsperson Web site, 2015a). However, it is unclear whether these services are accessible to parents with MI. The social services literature does not appear to discuss the accessibility of existing state-appointed advocacy bodies to the public (or more specifically, to parents with MI), or their benefit to those who access them.

Another avenue to fair process identified by study participants was through the legal system. Low-income families can receive legal aid services in the form of pro-bono legal services provided by the Legal Service Society (LSS) in BC (Legal Services Society Web site, 2015). However, as study participants noted, there are significant financial eligibility and issue-specific restrictions to legal aid that make this service virtually inaccessible (Brewin & Stephens, 2004;

Morrow et al., 2006; Tsoukalas & Roberts, 2002). Deep funding cuts to LSS in 2002 compromised low-income persons' access to fair process, especially impacting families, persons with disabilities, and women (Brewin & Stephens, 2004; Morrow et al., 2006). Poverty law representation (for people denied income or disability assistance) was eliminated (Brewin & Stephens, 2004; Morrow et al., 2006), and representation for family related issues (e.g., custody, access) limited to 'emergency situations' (see Legal Services Society Web site, 2015).

Overall, the study findings point to barriers to advocacy and legal aid services that may significantly impact the ability of parents with MI to access services and due process. The policies that create these barriers contribute to silencing the voices of parents with MI and their allies.

From the study participants' perspectives, these parallel processes of marginalization are, to use one participant's analogy, 'gears in the machine' that keeps those who have been historically marginalized rooted in disadvantage, poverty, illness and powerlessness. Within this power hierarchy, service participants and community service providers appear to make up the bottom tiers. The next section looks at this power hierarchy from a gendered perspective.

### **A gendered lens on manufacturing marginalization.**

It is a fact that studies of the experience of parenting with MI (e.g., Ackerson, 2003a; Nicholson, Sweeney, & Geller, 1998) and engagement of parents with services (e.g., Boyd, Diamond, & Bourjolly, 2006; Franks, Henwood, & Bowden, 2007; Nicholson et al., 2001; Pfefferle & Spitznagel, 2009; Reid et al., 2006; Reid et al., 2011; Shanley, Reid, & Evans, 2008), predominantly engage mothers as their participants (Nicholson et al., 2001). Hence, most of what we know about the experience of 'parents' with MI pertains to mothers. The failure of studies to ac-

knowledge the gender-specificity of findings is a major limitation — it precludes the examination of findings within a gendered context, thereby ignoring the intersection of factors such as systemic discrimination, experiences of violence, single motherhood, and poverty that persist within this context (Benbow, Forchuk, & Ray, 2011; Burke-Miller, 2010; Cook, 2003; Humphreys & Thiara, 2003; Nicholson et al. 2001).

The majority of study participants (six out of eight) were mothers, so the findings are best viewed with a gendered lens. From this perspective, the marginalization of certain groups, such as women, people of colour, the poor, and the disabled, comes into view as part of a historic continuum of discrimination (Benbow, Forchuk, & Ray, 2011; Burke-Miller, 2010; Cook, 2003; Humphreys & Thiara, 2003; Lie & Este, 1999; Randall, 1992; Young, 1994). The experiences of these groups are linked through the marginalizing, oppressing and violating socio-political forces of this continuum (Randall, 1992).

A gendered lens sees through the abstractions of service ‘provider’ and ‘participant’ to the people behind them — most of them women (Bloom, 2010) — whose health and behaviours are affected by the contexts in which they live and work. Significant determinants of health and MH include the experience of oppression and violence (World Health Organization [WHO], 2013) and socioeconomic conditions, such as quality of employment and work environment (Health Council of Canada [HCC], 2010; Mikkonen & Raphael, 2010; National Collaborating Centre for Determinants of Health [NCCDH], 2011; WHO, 2013).

It has been recognized that the setting of social, health and MH service organizations can be highly stressful (Knaak & Patten, 2014; Mental Health Commission of Canada [MHCC], 2013; Bloom, 2010). Study participants also noted what they perceived to be a crisis-driven and

at times chaotic nature of the work of system providers. Some saw providers' responses as a reflection of the challenges that these providers experienced in the workplace, for example, being stressed and "overloaded". In her analysis of the impact of organizational structures on the well-being of social service providers, Bloom (2010) suggests that responses to a highly stressful, rigid work setting and a domineering style of management can become synchronous with the response to the violence providers had experienced in their lives. Bloom suggests further that the impact of such an environment is especially felt by women providers, who are more likely to experience multiple forms of violence and discrimination (Benbow et al., 2011; Burke-Miller, 2010; Cook, 2003; HCC, 2010; Klein et al., 2008b; Mikkonen & Raphael, 2010; WHO, 2013). Bloom's (2010) analysis implies that social institutions, as microcosms of the larger society, reproduce the discrimination and violence against historically marginalized groups. Further, it points to the contribution of social institutions to the normalization of oppression and violence, through policy and practice.

A gendered analysis links service 'providers' and 'participants' through their sociopolitical context. It illustrates the challenges experienced on both sides of the 'us versus them' divide as symptoms of the same endemic social ills: inequality, injustice and marginalization (Benbow et al., 2011; Burke-Miller, 2010; Cook, 2003; HCC, 2010; Klein et al., 2008b; Mikkonen & Raphael, 2010).

However, neither service participants or providers are passive receptacles of discrimination, as evident in the study participants' accounts of how they, and some of the service providers they encountered, responded to the system.

### **Resisting the system — “You can’t give up!”**

Participants’ descriptions of how they and some of the service providers responded to the dominant system structures and processes pointed to multiple forms of resistance. Participants described challenging, complying, performing kindness, and ‘not giving up’ as their responses to the system. They also spoke of allies: exceptional service providers who worked with the parents, supporting them in their contact with the system.

Some participants described actively opposing what they saw as unjust and wrongful actions against them and their families, by directly challenging the persons they saw as responsible. Others pointed out that being outspoken required personal resources that were not always available, and that retaliation by the system could compromise supports. Hence, at times, complying with demands (however unfair or unreasonable these were) was the only option. This action required no less strength (and perhaps even more) than opposition. Participants also spoke of performing acts of kindness, such as providing information to their peers, volunteering in the community, or sharing the hope for change with their peers. While participants did not view them as resistance, these acts directly challenged the image of the ‘powerless victim’ of marginalization.

‘Not giving up’ can be seen as another subtle form of resistance. It was clearly the most critical and difficult to sustain. To ‘keep going,’ parents accessed every available avenue of support, including peer networks and peer support groups, and especially peer and professional advocates (as discussed earlier). Highlighting the importance of this, participants emphatically encouraged their peers to keep persevering: “You can’t give up!”

Participants also noted the work of the few professionals and organizations that aided them in their process. These allies provided vital support, collaborating with participants and

strengthening their response to the system through guidance and advocacy. Participants acknowledged the risks that were involved in this work, as it stood in opposition to the dominant system protocols and ways of working. Participants' accounts highlighted singular system providers who sidestepped or directly violated policy in an apparent attempt to resolve the tension between their professional duties and personal ethics. Gatenby & Hume (2004) propose that this tension is definitive of the work of allies, which often requires difficult choices that test the congruency between provider's ethics and actions.

### **Conclusion.**

Through the interrelated processes of stigmatizing, discriminating and silencing, the system appeared to methodically dismantle the rights of study participants to choose health and wellness for themselves and for their family. It further invalidated participants' right to fair treatment and due process, as well as their right to speak and be heard. Through select funding allocation, the system appears to impact the ability of allies to speak on behalf of parents with MI and other marginalized groups (Brewin & Stephens, 2004; Morrow et al., 2006; Sieppert, te Linde, & Rutherford, 2004).

However, as Margaret Randall (1992) asserts, where there is dominance, resistance is a certainty. *Resistance is happening*, being performed by service participants and their allies: peer and professional advocates as well as exceptional community and system service providers. The study findings point to the work of allies as critical to the ability of parents with MI to endure contact with the system. Moreover, building on this work may be a way of facilitating and sustaining the changes needed to ensure an easier, fairer process of engagement with services for parents with MI and their families.

## From problems to solutions

Study participants stressed their intent to support a transformation in the context of parenting services. Participants described a fragmented, restrictive and crisis-driven parenting services context. They spoke of being stigmatized, systemically discriminated against and silenced by the systems and service providers to whom they turned for help. They described their experience of system services as a process that manufactured the marginalization of parents with MI and their families. These findings underscore the need for change — especially within system policies and practices — that would result in meaningful supports for parents with MI and their families. Participants provided several recommendations for a way forward:

- Eliminate policies and practices that stigmatize, discriminate and marginalize parents with MI and their families
- Provide equitable, public access to all essential services (e.g., safe, affordable housing; food security; respite; psychiatric supports) and ensure that these supports are sufficient to meet the family's needs
- Expand the public health perspective to include prevention and recovery-based supports
- Create a strong network of community-based services that is visible and accessible and can offer tangible supports to the family
- Engage parents and families as partners in collective action, advocacy, service planning and evaluation; and support them to exercise their rights, *including their right to be heard*

Participants were clear that their voices have thus far been silenced and urged policy makers and service providers to hear and heed them. The next section amplifies their words by adding the chorus of voices from the literature in support of their recommendations.

**A change in perspective — the social justice approach (SJA).**

One of the key messages from study participants to service providers was that *discrimination* — especially denial or negation of rights to services, self-determination and parenthood — and *marginalization* in the form of social deprivation, exclusion and disempowerment are part of the daily reality of parents with MI in their engagement with parenting services. Participants implicated government institutions — “the system” of parenting services — in sustaining this status quo.

Social policies and practices of social institutions (e.g., governments, health authorities, public agencies) create the social, economic and political conditions that directly affect peoples’ health, social wellness and their ability to exercise their rights (Canadian Institute for Health Information [CIHI], & Statistics Canada, 2013; HCC, 2010; Mikkonen & Raphael, 2010; National Collaborating Centre for Determinants of Health [NCCDH], 2011; Ontario Ministry of Health and Long-Term Care [OMH], 2012; Organization for Economic Co-operation and Development [OECD], n.d.; Public Health Agency of Canada [PHAC], 2006; UN UN Department of Economic and Social Affairs [DESA], 2014; World Health Organization [WHO], 2013). The conditions generated by the current systems of MHS and social ‘welfare’ have resulted in unacceptable disparities in the health and wellness of the population, especially of persons with disabilities, single mothers, as well as persons (and especially women) and families living on low incomes (Food Bank Canada [FBC], 2014; Jategaonkar, & Ponic, 2010; Klein et al., 2008a, 2008b; Mikkonen & Raphael, 2010; Sieppert, te Linde, & Rutherford, 2004; Swanson et al., 2014; Tweddle, Battle, & Torjman, 2013; Wallace, Klein, & Reitsma-Street, 2006). These conditions perpetuate chronic marginalization and stigmatization of these groups, as well as parents with MI, and systemically

exclude them from full participation in society (Jategaonkar, & Ponic, 2010; Klein et al., 2008a, 2008b; Mikkonen & Raphael, 2010; Sieppert et al., 2004; Swanson et al., 2014; Tweedle et al., 2013; Wallace et al., 2006; UN DESA, 2014; WHO, 2013). The evidence of the extent of the impact of social institutions on the lives of individuals and families supports a change in perspective on social policy development — one that is focused on protection of rights, equitable access to social goods and services, social inclusion, and government accountability (HCC, 2010; Klein et al., 2008a, 2008b; Mikkonen & Raphael, 2010; NCCDH, 2011; Wallace et al., 2006; UN DESA, 2014; WHO, 2013). The social justice approach (SJA) (UN DESA, 2014) provides one platform from which to begin the necessary changes.

From a social justice perspective, governments and other social institutions that establish how access to social goods (e.g., housing, education, employment) and services (e.g., healthcare, income assistance, disability and family services) is accomplished are directly accountable for population outcomes (Rawls, 1999; UN DESA, 2006). The key principles of social justice are protection of human and civic rights; non-discrimination; and inclusion (Rawls, 1999; UN DESA, 2014). The SJA to policy and practice development (UN DESA, 2014) explicates the power imbalances between those who run the institutions and those who participate in them (Rawls, 1999; UN DESA, 2006). It presents responsibility and accountability as a function of power and privilege, such that those with more power and privilege have more social responsibility (Rawls, 1999; UN DESA, 2006). The SJA emphasizes the participation of all stakeholders in the community, including those who have been historically marginalized, in decision-making regarding how social goods and services are distributed (Rawls, 1999, UN DESA, 2006). It underscores collaboration as a means of achieving justice (Rawls, 1999, UN DESA, 2006).

The core of the SJA is a social contract (Rawls, 1999). To commit to this contract is to commit to work towards an equitable distribution of power between parties and within society as a whole (Rawls, 1999); that is, by removing barriers such as inequitable access to resources, and by facilitating power distribution (Rawls, 1999; UN DESA, 2014), through knowledge-sharing, advocacy, and building ‘bridges’ and partnerships. When the study participants spoke of what they valued in service provision, these are the actions they identified as empowering.

### **SJA and prevention.**

The study participants recommendations also indicate the need for a shift in focus from a narrow, crisis-driven, reactive service response to one of prevention. Support for applying the SJA to a prevention framework of service delivery can be found in the population health and social services literature that speaks to the deleterious impacts of health and social inequities (Arim, 2015; CIHI, & Statistics Canada, 2013; HCC, 2010; Klein et al., 2008a, 2008b; Mikkonen & Raphael, 2010; NCCDH, 2011; OHM, 2012; PHAC, 2006; Tjepkema, Wilkins, & Long, 2013).

There is evidence for a shift in focus in population health from individual attributes and behaviours (e.g., smoking, exercise) to broader social determinants of health (SDOH), especially social and economic factors (e.g., socioeconomic status [SES]) (HCC, 2010; Mikkonen & Raphael, 2010; NCCDH, 2011; PHAC, 2006; Sutcliffe, Snelling, & Lacle, 2010). Universal prevention approaches that target conditions that cause inequities in distribution of wealth and health are increasing being recognized as having the most benefit to the most people (HCC, 2010; Klein et al., 2008a, 2008b; Mikkonen & Raphael, 2010; NCCDH, 2011; OHM, 2012).

***Poverty reduction as prevention.***

Poverty reduction has been proposed as “a cross-cutting approach that could encompass multiple determinants [of health]” (NCCDH, 2011, p. iii), producing the most overall benefit (HCC, 2010; NCCDH, 2011). Within a comprehensive poverty reduction strategy (see Klien et al., 2008b), population-wide initiatives, such as enhancing social goods and services (e.g., housing, child care, adult education) are balanced with targeted services, that address the needs of the most marginalized groups (Klein et al., 2008b; Mikkonen & Raphael, 2010). Effective targeted services are the result off a strong network of community services that work collaboratively to increase service access and utilization (Cohen, Hall, Murphy, & Priest, 2009; Hinden, Biebel, Nicholson, & Mehnert, 2005; Kirby & Keon, 2006; MHCC, 2012; Mowbray, Nicholson, & Bel-lamy, 2003; Nicholson et al., 2001).

***Stigma-reduction as prevention.***

Stigma associated with MI has been nationally acknowledged as a major barrier to service access for people with MI (Kirby & Keon, 2006; Knaak & Patten, 2014; MHCC, 2013, 2012). Population-wide prevention initiatives that target stigma have been forwarded as a means of reducing these barriers (Jang, Chiriboga, & Becker, 2010; Kirby & Keon, 2006; MHCC, 2013c, 2012; WHO, 2013), thereby reducing inequities in access to health services and mental health services (MHS) (Jang et al., 2010; WHO, 2013).

The key strategies advanced in the literature are: increasing public awareness of the impact of stigma and discrimination (Benbow et al., 2011; Burke-Miller, 2010; Jang et al., 2010; Kirby & Keon, 2006; MHCC, 2012; MHCC, 2013c; WHO, 2013); increasing public mental health (MH) literacy (i.e., understanding of MH and illness and appropriate supports) (Jang et al.,

2010; Kirby & Keon, 2006; MHCC, 2012; MHCC, 2013c; WHO, 2013); increasing visibility of MHS in the community (Jang et al., 2010; Kirby & Keon, 2006; MHCC, 2012; MHCC, 2013c); and targeting stigma associated with MI within the health services sector (Knaak & Patten, 2014; MHCC, 2013b).

### ***Where's the evidence?***

Reducing inequities through population-wide and targeted initiatives can decrease the need for costly emergency and institutional care (Cohen et al., 2009; HCC, 2010; NCCDH, 2011). Community-based services reduce the pressure on hospital/emergency services and can be equally effective (Cohen et al., 2009). This frees up funding to be allocated to enhancing social goods and services (HCC, 2010). Conversely, decreased spending in these areas widens the inequity gap (HCC, 2010; OMH, 2012), generating the cycle of crises and illness and reactive crisis-driven service response (Food Bank Canada, 2014; Klein et al., 2008a, 2008b; Mikkonen & Raphael, 2010) — the cycle experienced by study participants.

Although evidence is only now building in support of the implementation of universal prevention efforts (Sutcliffe, Snelling, & Lacle, 2010; Federal, Provincial and Territorial Advisory Committee on Population Health [FPTACPH], 1999), the high human and fiscal costs of neglecting prevention (CIHI, 2008; Cohen et al., 2012; FPTACPH, 1999; Government of Canada, 2006; Health Canada, 2002; Jacobs et al., 2008) are hard to ignore. The question is: Are these costs evidence enough for change?

### **Recovery-based services within the prevention framework.**

Targeted recovery-based services that address the needs of specific population groups, such as persons and families affected by MI, can provide the necessary counterpart to universal prevention strategies (Klein et al., 2008a, 2008b; Trainor, Pomeroy, & Pape, 2004).

Recovery-based supports for persons with MI are based on the principle that social well-being and meaningful participation in all aspects of life are possible despite illness (Beresford & Wilson, 2002; Marsh, 2000, 2009; Nicholson et al., 2010; Trainor et al., 2004; WHO, 2013), especially when adequate supports are in place for the person and family (Marsh, 2009; Nicholson et al., 2010; Trainor et al., 2004; WHO, 2013). These services are inherently strength- and future-oriented (Marsh, 2009; Nicholson et al., 2010; Trainor et al., 2004), and *person-centred* (Coursey et al., 2000; Hinden, Biebel, Nicholson, & Mehnert, 2005; Hinden, Biebel, Nicholson, Henry, & Katz-Leavy, 2006; Hinden, Wolf, Biebel, & Nicholson, 2009; Huntsman, 2008; Marsh, 2009; Mowbray, Nicholson, & Bellamy, 2003; Nicholson, 2010; Walling & Marsh, 2009); that is, they attend to the “human context of mental illness” (Marsh, 2000, p. 1456), rather than focus solely on the pathology or diagnostic category (Beresford & Wilson, 2002; Marsh, 2000).

Recovery services position participants as agents of their own process (Hinden et al., 2006; Hinden et al., 2009; Marsh, 2000; Nicholson, 2010) and support self-determination (Hinden et al., 2006; Hinden et al., 2009; Coursey et al., 2000; Mowbray et al., 2003; Nicholson, 2010), including the ability to choose treatment (Beresford & Wilson, 2002; Marsh, 2000; WHO, 2013). However, they also recognize the interdependence of human lives and the impact of family and social contexts on individual health and wellness (Coursey et al., 2000; Hinden et al., 2005; Hinden et al., 2006; Hinden et al., 2009; Huntsman, 2008; Marsh, 2009; Mowbray et al.,

2003; Nicholson, 2010; Walling & Marsh, 2009). Hence, supports for the family (Hinden et al., 2005; Hinden et al., 2006; Hinden et al., 2009) and comprehensive supports for the children (Hinden et al., 2005; Marsh, 2009; Nicholson, 2010) are provided.

Additionally, these services are trauma-informed (Nicholson, 2010); that is, they are based on an understanding of the impact of trauma on health, behaviour and on the process of recovery (Urquhart et al., 2013). This is especially relevant to supporting mothers with MI and their families “given the prevalence of victimization, the witnessing of violence, [and] serious disruptions and losses [in their lives]” (Nicholson, 2010, p. 370).

“Perhaps the greatest trauma is prompted by the loss of custody of a child” (Nicholson, 2010, p. 370). Study participants’ accounts clearly evidenced the profound grief associated with this loss. Their accounts also indicated that hope — the cornerstone of recovery (Beresford & Wilson, 2002; Marsh, 2000; Nicholson, 2010; WHO, 2013) — may be inextricably linked to their children. Virtually all of the study participants stated that their children and their children’s future were their motivation for ‘not giving up’ in the face of the daily onslaught of challenges. Findings of other studies that have engaged mothers with MI (e.g., Ackerson, 2003a; Nicholson et al., 2001; Perera et al., 2015) reflect this observation. Hence, help with managing the impact of custody loss and support through reunification may be especially relevant to *parental* recovery (Marsh, 2009; Nicholson et al., 2006).

Within a prevention framework, recovery supports are aimed at relapse prevention (Walling & Marsh, 2000) and minimizing the risk of relapse to the person and family (Hinden, Biebel, Nicholson, & Mehnert, 2005; Hinden, Biebel, Nicholson, Henry, Katz-Leavy, 2006; Huntsman, 2008; Lees et al., 2002; Marsh, 2009; Mowbray, Nicholson, & Bellamy, 2003;

Nicholson, 2010; Walling & Marsh, 2000). Assistance includes access to cultural, social and economic resources (Morrow, Frischmuth, & Johnson, 2006; Trainor et al., 2004; WHO, 2013) imperative for health and wellness (Klein et al., 2008a, 2008b; Mikkonen & Raphael, 2010; NC-CDH, 2011; OHM, 2012; PHAC, 2006; Tjepkema et al., 2013), as well as for maintaining parenting capacity (Guterman & Hahm, 2001; Min Park, Solomon, & Mandell, 2006; Nicholson, 2010; Nicholson et al., 2001). A strong support system in the community is essential to sustaining recovery gains and preventing relapse of illness (Nicholson et al., 2001; Trainor et al., 2004; Walling & Marsh, 2000).

Importantly, recovery-based services recognize the episodic nature of illness (Marsh, 2009; Nicholson, 2010; Trainor et al., 2004; Walling & Marsh, 2000). Resources are made available to the parent and family *when they need them* (Trainor et al., 2004; Walling & Marsh, 2000), and contingency planning, especially for times of hospitalization, is encouraged (Lees et al., 2002).

There is emerging evidence that centralized recovery-based community MHS that provide least-barrier access to a range of resources for parents with MI and their families achieve significant engagement rates, maintain utilization of services over time, and result in positive health and social outcomes for the parent and family (Hinden et al., 2005; Hinden et al., 2006; Hinden et al., 2009; Huntsman, 2008; Nicholson et al., 2001; Nicholson, 2010). The broader the spectrum of the service (i.e., the more social determinants of health it targets), the better the outcome (Hinden et al., 2006; Nicholson et al., 2001).

### **From collaboration to accountability.**

Population-wide and targeted prevention efforts aimed at the social determinants of health (SDOH) must include cross-disciplinary initiatives (HCC, 2010; Klein et al., 2008a, 2008b; Mikkonen & Raphael, 2010; NCCDH, 2011; OHM, 2012; PHAC, 2006; UN DESA, 2004; WHO, 2013), since SDOH clearly lie beyond the reach of any one government or ministry (HCC, 2010). It follows, that collaboration is a prerequisite to a comprehensive continuum of services.

Many advocates of system change argue cogently for a whole-of-government approach (FBC, 2014; HCC, 2010; Klein et al., 2008a, 2008b; Representative for Children and Youth [RCY], 2014b). This is “a movement that is attempting to change the work of the public sector from a focus on the individual work of ministries or departments …to a focus on complex issues that can only be addressed through a collaborative, integrated approach” (HCC, 2010, p.14).

Study participants’ descriptions of the context of parenting services point to potential key players in cross-ministerial and cross-disciplinary partnerships: *social and child ‘welfare’ systems*. It may therefore be particularly important to examine and revamp existing relationships within and between these ministries (Darlington, Feeney, & Rixon, 2005; Sheehan, 2004).

Moreover, a continuum of services to families that promote health, prevent illness and support recovery would require coordinated efforts on all fronts: “all levels of government, multiple government departments, communities, researchers, the non-profit sector, and the private sector” (HCC, 2010, p. 8). ‘Top-down’ efforts (e.g., policy and strategic guidance) will require uptake from the ‘ground level’ to succeed (HCC, 2010; NCCDH, 2011). Therefore, strong local

leadership will be decisive to implementation (Darlington, Feeney, & Rixon, 2005; HCC, 2010; NCCDH, 2011) and to sustainability of the change in practice (Lauritzen & Reedtz, 2015).

Clearly, for these initiatives to succeed, all levels of policy makers and service providers will need to talk to each other and coordinate their efforts. Perhaps the most critical element to success, however, is the collaboration between policy makers, providers *and service participants* (Coursey et al., 2000; HCC, 2010; Hinden et al., 2006; Hinden et al., 2009; Huntsman, 2008; Marsh, 2009; Mowbray et al., 2003; Nicholson, 2010; Klein et al., 2008a, 2008b; Mikkonen & Raphael, 2010; MHCC, 2013a; Rawls, 1999; UN DESA, 2004; WHO, 2013).

The core of the SJA is a social contract (Rawls, 1999) that promotes equitable distribution of power through the full participation of all stakeholders — including persons who have traditionally been marginalized in society — in decision-making regarding distribution of social wealth (Rawls, 1999). From this perspective, collaboration between all stakeholders provides a vehicle for achieving justice (Rawls, 1999). Furthermore, recovery-based services underscore social inclusion and meaningful participation in society (Hinden et al., 2006; Hinden, Wolf, Biebel, & Nicholson, 2009; Marsh, 2000; Nicholson, 2010; Trainor et al., 2004). Hence, collaboration may also be a vehicle of recovery. Moreover, as a means of connecting those who create policy and those who administer it with those who experience its impacts, collaboration may be a vital link between intent and accountability.

### **Working as allies to achieve change.**

Participants' accounts highlighted the work of allies: peer and professional advocates and other professionals and organizations who supported them in their contact with system services and in their process of recovery. As noted earlier, *resistance is happening and good work is being*

*done.* This work may hold the key to ensuring that intentions behind proposed changes are realized into action.

Expansion of advocacy roles within community organizations is one step towards strengthening the work of allies (Benbow, Forchuk, & Ray, 2011; Guterman & Hahm, 2001; Marsh, 2000). Supporting peer-led organizations is another. These organizations have proven records of challenging discriminatory, inadequate or inappropriate policies and practices (Beresford & Wilson, 2002; Guterman & Hahm, 2001). Engaging with peer-support and peer-advocacy groups as part of every-day practice of individual providers and organizations can enhance the capacity of all parties for collective action in opposition to injustice (Burke-Miller, 2010; Guterman & Hahm, 2001).

On a more individual level, Townsend (1998) suggests becoming “constructively oppositional” (p. 170) to the dominant structures and workplace practices: exposing privilege for what it is and changing approach to practice — for example, changing everyday language (e.g., from ‘cases’ to people) and working “where and when help is needed” (Townsend, 1998, p. 171). The accounts of study participants indicate that such seemingly small acts can have significant impacts on individuals and families.

As Townsend (1998) notes, consistent with many assertions in the literature reviewed in this chapter, “Many people would like to change the system” (p. 170). But individuals or isolated initiatives are easily opposed or disarmed by the dominant powers (Randall, 1992). The key to successful resistance is in collective action (Guterman & Hahm, 2001; Randall, 1992; Townsend, 1998; Young, 1994): in the “joining of democratic collectives that foster bonds of solidarity and

bring the actions of many individuals together toward ...social transformation" (Young, 1994, p. 50-51).

A SJA applied to a comprehensive prevention framework has the potential to create a community of services that embodies the recommendations of study participants. Collectively, service participants, providers, policy makers, and researchers stand the greatest chance of realizing this potential (Guterman & Hahm, 2001; Klein et al., 2008a, 2008b; Townsend, 1998; Young, 1994).

## **Conclusion**

Parents with mental illness (MI) face considerable day-to-day challenges that can affect parental and family functioning (Mordoch & Hall, 2002; Nicholson, Biebel, Hinden, Henry, & Stier, 2001; Reupert & Maybery, 2007; Smith, 2004; Vostanis et al., 2006). This study offered a glimpse into the lived experience of parents with MI, *from their perspective* — in particular, their attempt to mitigate the difficulties of parenting with MI through the use of professional supports.

Participants identified the services context as highly fragmented and characterized by restrictive and reactive service response. Participants' accounts implicated service deficits — especially neglect of prevention — as generating a cycle of poverty, illness and service dependence for the parents with MI and families. This was highlighted by the participants' description of the experience of marginalization as directly linked to their experience of services. These findings situate parents with MI as one of the historically under-serviced and marginalized groups in society, along with persons with disabilities and single mothers, in particular (Klein et al., 2008b; Mikkonen & Raphael, 2010; Trainor, Pomeroy, & Pape, 2004; WHO, 2013; UN Department of Economic and Social Affairs [DESA], 2014). However, the parents' experience of the deficits of

the parenting services context is unique, in that the consequences of these gaps intersect with and amplify the multiple challenges of parenting with MI. The result is a cycle of *personal and family crises*, the impacts of which may be felt for many years or even reverberate through generations.

The extent of the effect of the services context on the parent and family is not acknowledged in the MHS literature. Overall, there is a large gap in the understanding of how parents with MI engage with services or of the outcome of this process (Ackerson, 2003b; Maybery & Reupert, 2009; Mordoch & Hall, 2002; Nicholson, 2009; Nicholson, Biebel, Katz-Leavy, & Williams, 2004). There is, however, recognition that when essential supports (e.g., income subsidy, mental health services, respite care) are missing or inadequate, the difficulties of parenting with MI are significantly exacerbated (Bassett, Lampe, & Lloyde, 1999; Mensah & Kiernan, 2010; Mowbray, Oyserman, & Ross, 1995; Pfefferle & Spitznagel, 2009; Reupert & Maybery, 2007; Smith, 2004). Additionally, there is a mountain of studies identifying risks of parental MI to the child (e.g., Bassani, Padoin, & Vendhuizen, 2008; Mensah & Kiernan, 2010; Mordoch & Hall, 2002; Nicholson, et al., 2001; Pfefferle & Spitznagel, 2009; Reupert & Maybery, 2007; Smith, 2004; Sui Mui & Ying Suet Chau, 2010; Vostanis et al., 2006; Weissman et al., 2006). In spite of this evidence, government policies continue to ignore the unique challenges and needs of these parents and families. This is evident in the national mental health strategy (Mental Health Commission of Canada, 2012) and the BC counterpart (Ministry of Health & MCFD, 2010). Not one healthcare policy in Canada acknowledges the needs of parents with MI and their families.

The lack of policy attention appears to be reflected in the insufficient response of social and mental health services to the needs of parents with MI and their families (Benbow, Forchuk,

& Ray, 2001; Guterman & Hahm, 2001; Hinden, Biebel, Nicholson, Henry, & Katz-Leavy, 2006; Mowbray, Nicholson, & Bellamy, 2003; Walling & Marsh, 2000). This is especially evident in the lack of services capable of comprehensively addressing the needs of *the parent and family* (Mowbray et al., 2003; Nicholson et al., 2001; Reupert and Maybery, 2007, 2011).

These study findings, and much of the literature presented in this discussion, suggest that a change in perspective to policy and practice is necessary — one that calls upon social institutions responsible for optimizing health to be accountable for the outcomes on families affected by parental MI. The social justice approach (SJA) (UN DESA, 2006) is proposed here as one possible platform for change. The findings further indicate a need for a strong prevention framework that includes both population-wide initiatives (e.g., adequate income assistance, social housing, child care) and targeted recovery-based services.

There is sufficient evidence to suggest that the changes proposed may not only improve the lives of people directly impacted by the system, but ensure a healthy future for all Canadians (Canadian Institute for Health Information [CIHI], & Statistics Canada, 2013; Health Council of Canada [HCC], Mikkonen & Raphael, 2010; National Collaborating Centre for Determinants of Health [NCCDH], 2011; Ontario Ministry of Health and Long-Term Care [OMH], 2012; Public Health Agency of Canada [PHAC], 2006).

The road ahead will require dialogue among multiple stakeholders at every level (federal, provincial, regional, and community) that *must include people with lived experience* — this was clearly articulated by the study participants. Their voices are joined by many others (e.g., (Coursey et al., 2000; HCC, 2010; Klein, 2008a, 2008b; MHCC, 2012, 2013a; Marsh, 2009; Mikkonen & Raphael, 2010; Nicholson, 2010; WHO, 2013) who see the engagement of people

with lived experience of the impacts of policy and practice (i.e., intentions and actions) as a key to progressive, responsive and responsible change.

Participants urged providers, academics, policy-makers, and governments not only to hear, but to *heed* them. They urged dialogue *and* action. Action will necessitate a sharing of power within and between governments, as well as between governments and people. It will require a recognition by the governments of “a free and democratic society” (Canadian Charter of Rights and Freedoms, 1982, s.1) that they are obligated to the people to uphold the universal, indivisible and interdependent human rights and freedoms (UN General Assembly, 1993; UN OHCHR, 1996) — to which every one is entitled equally and without discrimination (UN General Assembly, 2006, 1948) — including the right to be treated with dignity, the right to choose health and wellness, the right to social inclusion, and the right to exercise the power of voice in support of change.

## References

- Abrams, L. S. (2010). Sampling ‘hard to reach’ populations in qualitative research: The case of incarcerated youth. *Qualitative Social Work, 9*(4), 536–550.  
doi: 10.1177/1473325010367821
- Ackerson, B. J. (2003a). Coping with the dual demands of severe mental illness and parenting: The parents’ perspective. *Families in Society: The Journal of Contemporary Human Services, 84*(1), 109-118.
- Ackerson, B. J. (2003b). Parents with serious and persistent mental illness: Issues in assessment and services. *Social Work, 48*(2), 187-194.
- Agllias, K. (2011). Utilizing participants’ strengths to reduce risk of harm in a study of family estrangement. *Qualitative Health Research, 21*(8), 1136-1146.  
doi: 10.1177/10497323114505065
- Ahern, K. (2012). Informed consent: Are researchers accurately representing risks and benefits? *Scandinavian Journal of Caring Sciences, 26*, 671-678.  
doi: 10.1111/j.1471-6712.2012.00978.x
- Alakus, C., Conwell, R., Gilbert, M., Buist, A., & Castle, D. (2007). The needs of parents with a mental illness who have young children: An Australian perspective on service delivery options. *International Journal of Social Psychiatry, 53*(4), 333-339.  
doi: 10.1177/0020764006074543
- Alpert, L. T. (2005). Research review: Parents’ service experience — a missing element in research on foster care case outcomes. *Child and Family Social Work, 10*(4), 361-366.  
doi: 10.1111/j.1365-2206.2005.00387.x

- Amedani, B. K., & Hock, R. M. (2012). Health care access and treatment for children with co-morbid autism and psychiatric conditions. *Social Psychiatry and Psychiatric Epidemiology*, 47(11), 1807-1814. doi: 10.1007/s00127-012-0482-0
- Arim, R. (2015). *A profile of persons with disabilities among Canadians aged 15 or older: Canadian survey on disability, 2012*. Retrieved from  
<http://www.statcan.gc.ca/pub/89-654-x/89-654-x2015001-eng.pdf>
- Bassani, D. G., Padoin, C. V., & Veldhuizen, S. (2008). Counting children at risk: Exploring a method to estimate the number of children exposed to parental mental illness using adult health survey data. *Social Psychiatry and Psychiatric Epidemiology*, 43(11), 927-935.  
doi: 10.1007/s00127-008-0376-3
- Bassett, H., Lampe, J., & Lloyd, C. (1999). Parenting: Experiences and feelings of parents with a mental illness. *Journal of Mental Health*, 8(6), 597–604.
- Battered Women's Support Services (2015). The facts on violence against women. Retrieved September 30, 2015, from  
<http://www.bwss.org/resources/information-on-abuse/numbers-are-people-too/>
- Benbow, S., Forchuk, C., & Ray, S. L. (2011). Mothers with mental illness experiencing homelessness: a critical analysis. *Journal of Psychiatric and Mental Health Nursing*, 18, 687-695. doi: 10.1111/j.1365-2850.2011.01720.x
- Beresford, P., & Wilson, A. (2002). Genes spell danger: Mental health services users/survivors, bioethics and control. *Disability and Society*, 17(5), 541-553.  
doi: 10.1080/09687590220148513.

BC Mental Health and Substance Use Services. (2013). Adult Clinics and Services.

Retrieved from

<http://wwwbcmhsus.ca/programs-and-services/adult-clinics-and-services>

BC Non-Profit Housing Association. (2013). *Preparing for the expiry of operating*

*agreements.* Retrieved from

[http://bcnpha.ca/media/Research/EOA\\_newsletter\\_-\\_FINAL.pdf](http://bcnpha.ca/media/Research/EOA_newsletter_-_FINAL.pdf)

Beardslee, W. R., & Gladstone, T. R. G. (2001). Prevention of childhood depression: Recent

findings and future prospects. *Society of Biological Psychiatry*, 49, 1101-1110.

Beardslee, W. R., Wright, E. J., Gladstone, T. R., & Forbes, P. (2007). Long-term effects from a randomized trial of two public health preventative interventions for parental depression.

*Journal of Family Psychology*, 21(4), 703-713. doi: 10.1037/0893-3200.21.4.703

Beuer, F., & Roth, W-M. (2003). Subjectivity and reflexivity in the social sciences:

Epistemic windows and methodological consequences. *Forum Qualitative*

*Sozialforschung/Forum: Qualitative Social Research*, 4(2), n.p. Retrieved

from <http://www.qualitative-research.net/index.php/fqs/article/view/698>

Bloom, S. (2010). Organizational stress and trauma-informed services. In B. Lubotsky Levin and

A. Becker (Eds.), *A public health perspective of women's mental health*. Retrieved from

Springer:

[http://link.springer.com.ezproxy.library.uvic.ca/chapter/10.1007/978-1-4419-1526-9\\_15](http://link.springer.com.ezproxy.library.uvic.ca/chapter/10.1007/978-1-4419-1526-9_15)

Boyd, R. C., Diamond, G. S., & Bourjolly, J. N. (2006). Developing a family-based

depression prevention program in urban community mental health clinics: A

qualitative investigation. *Family Processes*, 45(2), 187-203.

- Boydell, K. M., Pong, R., Volpe, T., Tilliczek, K., Wilson, E., & Lemieux, S. (2006). Family perspectives on pathways to mental health care for children and youth in rural communities. *Journal of Rural Health*, 22(2), 182–188.
- Brannan, A. M., & Heflinger, C. A. (2006). Caregiver, child, family, and service system contributors to caregiver strain in two child mental health service systems. *Journal of Behavioural Health Services & Research*, 33(4), 408-422.
- Brewin, A., & Stephens, L. (2004). *Legal aid denied: women and the cuts to legal services in BC*. Available from West Coast Leaf: <http://www.westcoastleaf.org>
- Bringewatt, E. H., & Gershoff, E. T. (2010). Falling through the cracks: Gaps and barriers in the mental health system for America's disadvantaged children. *Children and Youth Services Review*, 32, 1291-1299. doi: 10.1016/j.chillyouth.2010.04.021
- Bryant, A., & Charmaz, K. (2007). Grounded theory research: Methods and practices. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of Grounded Theory*. Thousand Oaks, CA: Sage.
- Burke-Miller, J. K. (2010). Social and community contexts. In B. Lubotsky Levin and A. Becker (Eds.), *A public health perspective of women's metal health*. Retrieved from Springer: [http://link.springer.com.ezproxy.library.uvic.ca/chapter/10.1007/978-1-4419-1526-9\\_17](http://link.springer.com.ezproxy.library.uvic.ca/chapter/10.1007/978-1-4419-1526-9_17)
- Burnett-Ziegler, I., & Lyons, J. S. (2009). Caregiver factors predicting service utilization among youth participating in a school-based mental health intervention. *Journal of Child and Family Studies*, 19, 572-578. doi: 10.1007/s10826-009-9331-5
- Burnett-Ziegler, I., Walton, M. A., Ilgen, M., Barry, K., Chermack, S. T., Zucker, R. A., Zimmerman, M. A., Booth, B. M., & Blow, F. C. (2012). Prevalence and correlates

of mental health problems and treatment among adolescents seen in primary care.

*Journal of Adolescent Health, 50(6), 559-564. doi: 10.1016/j.jadohealth.2011.10.005*

*Canadian Bill of Rights*, S.C. 1960 c. 44. Retrieved from

<http://laws-lois.justice.gc.ca/PDF/C-12.3.pdf>

*Canadian Charter of Rights and Freedoms*, s 2, Part I of the *Constitution Act, 1982*, being

Schedule B to the Canada Act 1982 (UK), 1982 c. 11. Retrieved from

<http://laws-lois.justice.gc.ca/eng/const/page-15.html>

*Canadian Human Rights Act*, R.S.C. 1985 c. H-6. Retrieved from

<http://laws-lois.justice.gc.ca/eng/acts/H-6/>

Canadian Institute for Health Information [CIHI]. (2008). *The cost of acute care hospital stays*

*by medical condition in Canada, 2004-2005*. Retrieved from

[https://secure.cihi.ca/free\\_products/nhex\\_acutecare07\\_e.pdf](https://secure.cihi.ca/free_products/nhex_acutecare07_e.pdf)

CIHI. (2009, February 24). *The association between socio-economic status and inpatient*

*hospital service use for depression*. Retrieved from

<http://www.cmha.ca/public-policy/research-reports/>

CIHI. (2012, March). *Supporting factors influencing health: The role of social support in*

*reducing psychological distress*. Retrieved from

[https://secure.cihi.ca/free\\_products/AiB\\_ReducingPsychological%20DistressEN-web.pdf](https://secure.cihi.ca/free_products/AiB_ReducingPsychological%20DistressEN-web.pdf)

CIHI & Statistics Canada. (2013). *Health indicators 2013*. Retrieved from

[https://secure.cihi.ca/free\\_products/HI2013\\_EN.pdf](https://secure.cihi.ca/free_products/HI2013_EN.pdf)

Canadian Women's Foundation (2015). The facts on violence against women. Retrieved

September 30, 2015, from <http://www.canadianwomen.org/facts-about-violence#1>

- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative research*. Thousand Oaks, CA: Sage.
- Chien, W., & Norman, I. (2009). The effectiveness and active ingredients of mutual support groups for family caregivers of people with psychotic disorders: A literature review. *International Journal of Nursing Studies*, 46(12), 1604-1623.
- Coast Mental Health. (2014). About Coast. Retrieved from  
<http://www.coastmentalhealth.com/about-coast>
- Cohen, M., Hall, N., Murphy, J., & Priest, A. (2009). *Innovations in community care: From pilot project to system change*. Available from Policy Alternatives:  
<https://www.policyalternatives.ca/publications/reports/innovations-community-care>
- Cohen, M., McGregor, M., Ivanova, I., & Kinkaid, C. (2012, January). *Beyond the hospital walls: Activity based funding versus integrated health care reform*. Retrieved from  
[http://www.policyalternatives.ca/sites/default/files/uploads/publications/BC%20Office/2012/01/CCPA-BC\\_ABF\\_2012\\_Summary.pdf](http://www.policyalternatives.ca/sites/default/files/uploads/publications/BC%20Office/2012/01/CCPA-BC_ABF_2012_Summary.pdf)
- Compton, M. T., Kaslow, N. J., & Walker, E. F. (2004). Observations on parent/family factors that may influence the duration of untreated psychosis among African American first-episode schizophrenia-spectrum patients. *Schizophrenia Research*, 68, 373-385.  
doi: 10.1016/j.schres.2003.09.001
- Cook, J. A. (2003). Depression, disability, and rehabilitation services for women. *Psychology of Women Quarterly*, 27(2), 121-129. doi: 10.1111/1471-6402.00092.

- Coursey, R., Curtis, L., Marsh, D. T., Campbell, J., Harding, C., Spaniol, L....Stratoudakis, J. (2000). Competencies for direct service staff members who work with adults with severe mental illness in outpatient public mental health/managed care systems. *Psychiatric Rehabilitation Journal*, 23(4), 370-377.
- Darlington, Y., Feeney, J. A., & Rixon, K. (2005). Interagency collaboration between child protection and mental health services: Practices, attitudes and barriers. *Child Abuse & Neglect*, 29, 1085-1098. doi:10.1016/j.chabu.2005.04.005
- David, H. D., Styron, T., & Davidson, L. (2011). Supported parenting to meet the needs and concerns of mothers with severe mental illness. *American Journal of Psychiatric Rehabilitation*, 14(2), 137-153. doi: 10.1080/15487768.2011.569698.
- Denzin, N. K. (2010). Grounded and indigenous theories and the politics of pragmatism. *Sociological Inquiry*, 80(2), 296-312. doi: 10.1111/j.1475-682X.2010.00332.x
- Doyle, O., Joe, S., & Caldwell, C. H. (2012). Ethnic differences in mental illness and mental health service use among Black fathers. *American Journal of Public Health*, 102(S2), S222-S231. doi: 10.2105/AJPH.2011.300446
- Este, D. (1999). Social work and cultural competency. In Gwat-Yong Lie and D. Este, *Professional social service delivery in a multicultural world* (pp. 27-45). Available from <http://site.ebrary.com.ezproxy.library.uvic.ca>
- Farmer, E. M. Z., Burns, B. J., Angold, A., & Costello, E. J. (1997). Impact of children's mental health problems on families: Relationships with services use. *Journal of Emotional and Behavioural Disorders*, 5(4), 230-238. doi: 10.1177/106342669700500406

Federal, Provincial and Territorial Advisory Committee on Population Health (1999). *Statistical report on the health of Canadians*. Retrieved from <http://www.statcan.gc.ca/pub/82-570-x/82-570-x1997001-eng.pdf>

Finello, K. M., & Poulsen, M. K. (2011). Unique system of care issues and challenges in serving children under age 3 and their families. *American Journal of Community Psychology*, 49, 417-429. doi: 10.1007/s10464-011-9458-6

First Call: BC Child and Youth Advocacy Coalition. (2014, November). *2014 child poverty report card*. Available from Still 1 in 5: <http://still1in5.ca>

Forthergill, A., Northway, R., Allen, J., & Sinfield, M. (2011). Role of collaboration in providing holistic care for young people. *Mental Health Practice*, 14(10), 22-26.

Food Banks Canada. (2014). *Hunger Count 2014*. Available from <http://www.foodbankscanada.ca>

Franks, W., Henwood, K., & Bowden, G. (2007). Promoting maternal mental health: Women's strategies for presenting a positive identity and the implications for mental health promotion. *Journal of Public Mental Health*, 6(2), 40-51.

Fraser, E., & Pakenham, K. I. (2008). Evaluation of a resilience-based intervention for children of parents with mental illness. *Australian and New Zealand Journal of Psychiatry*, 42(12), 1041-1050.

Gaskin, D. J., Kouzis, A., & Richard, P. (2008). Children's and adolescents' use of mental health care is a family matter. *Medical Care Research and Review*, 65(6), 748-762. doi: 10.1177/1077558708320988

Gatenby, B., & Hume, K. M. (2004). Powerful discourses for social services. *Journal of*

- Organizational Change Management*, 17(3), 269-280.
- Gladstone, B. M., Boydell, K. M., Seeman, M. V., & McKeever, P. D. (2011). Children's experiences of parental mental illness: A literature review. *Early Intervention in Psychiatry*, 5, 271-289.
- Glasser, B. G., & Strauss, A. L. (1967). *The discovery of Grounded Theory: Strategies for qualitative research*. Piscataway, NJ: Aldine Transaction.
- Goldberg, M., & Long, A. (2003). *A path to poverty: A review of child and family poverty conditions in British Columbia*. Available from The Social Planning and Research Council of BC: <http://www.sparc.bc.ca/resources-and-publications/category/43?start=10>
- Government of Canada. (2006). *The human face of mental health and mental illness in Canada*. Retrieved from [http://www.mooddisorderscanada.ca/documents/Publications/Human%20Face%20of%20Mental%20Illness%20in%20Canada\\_EN.pdf](http://www.mooddisorderscanada.ca/documents/Publications/Human%20Face%20of%20Mental%20Illness%20in%20Canada_EN.pdf)
- Gurstein, P., Goldberg, M., Fuller, S., Kershaw, P., Pulkingham, J., & Vilches, S. (2008). *Precarious and vulnerable: Lone mothers on income assistance*. Available from The Social Planning and Research Council of BC: <http://www.sparc.bc.ca/resources-and-publications/category/43?start=30>
- Guterman, N. B., & Hahm, H. (2001). Empowering Parents in Home Visitation. In N. B. Guterman, *Stopping child maltreatment before it starts: Emerging horizons in early home visitation services* (pp. 162-187). Available from <http://knowledge.sagepub.com>
- Health Canada (2002). *A report on mental illnesses in Canada*. Retrieved from <http://www.phac-aspc.gc.ca/publicat/miic-mmac/index-eng.php>

Health Council of Canada (2010). *Stepping it up: Moving the focus from health care in Canada to a healthier Canada*. Retrieved from  
[http://www.healthcouncilcanada.ca/rpt\\_det.php?id=162](http://www.healthcouncilcanada.ca/rpt_det.php?id=162)

Hinden, B., Biebel, K., Nicholson, J., & Mehnert, L. (2005). The Invisible Children's Project: Key ingredients of and intervention for parents with mental illness. *Journal of Behavioural Health Services & Research*, 32(4), 393-408.

Hinden, B., Biebel, K., Nicholson, J., Henry, A., & Katz-Leavy, J. (2006). A survey of programs for parents with mental illness and their families: Identifying common elements to build the evidence base. *Journal of Behavioural Health Services & Research*, 33(1), 21-38.

Hinden, B., Wolf, T., Biebel, K., & Nicholson, J. (2009). Supporting Clubhouse members in their roles as parents: Necessary conditions for policy and practice initiatives. *Psychiatric Rehabilitation Journal*, 33(2), 98-105.

*Human Rights Code*, R.S.B.C. 1996 c. 210. Retrieved from

[http://www.bclaws.ca/EPLibraries/bclaws\\_new/document/ID/freeside/00\\_96210\\_01](http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_96210_01)

Humphreys, C., & Thiara, R. (2003). Mental health and domestic violence: 'I call it symptoms of abuse'. *The British Journal of Social Work*, 33(2), 209-226. doi: 10.1093/bjsw/33.2.209

Huntsman, L. (2008). Parents with mental health issues: Consequences for children and effectiveness of interventions designed to assist children and their families.

Retrieved from [http://www.community.nsw.gov.au/docswr/\\_assets/main/documents/research\\_parentalmentalhealth.pdf](http://www.community.nsw.gov.au/docswr/_assets/main/documents/research_parentalmentalhealth.pdf)

- Israel, M., & Hay, I. (2008). Informed consent. In L. M. Given, (Ed.), *The SAGE encyclopedia of qualitative research methods* (Informed consent). Retrieved from  
<http://www.stiba-malang.com/uploadbank/pustaka/RM/QUALITATIVE%20METHOD%20SAGE%20ENCY.pdf>
- Jacobs, P., Yim, R., Ohinmaa, A., Eng, K., Dewa, C. S., Bland, R., Block, R., & Slomp, M. (2008). Expenditures on mental health and addictions for Canadian provinces in 2003 and 2004. *Canadian Journal of Psychiatry*, 53(6), 306-313.
- Jang, Y., Chiriboga, D. A., & Becker, M. A. (2010). Racial and ethnic disparities. In B. Lubotsky Levin and A. Becker (Eds.), *A public health perspective of women's mental health*. Retrieved from Springer:  
[http://link.springer.com.ezproxy.library.uvic.ca/chapter/10.1007/978-1-4419-1526-9\\_18](http://link.springer.com.ezproxy.library.uvic.ca/chapter/10.1007/978-1-4419-1526-9_18)
- James, E. L., Fraser, C., & Talbot, L. (2007). Vulnerable children in families affected by parental mental illness: The role of theory in programme development. *Vulnerable Children and Youth Studies*, 2(2), 142-153.
- Jategaonkar, N., & Ponic, P. (2010). Unsafe and unacceptable housing: health and policy implications for women leaving violent relationships. *Women's Health and Urban Life*, 10(1), 32-58. Retrieved from  
[https://tspace.library.utoronto.ca/bitstream/1807/27218/1/10.1\\_jategaonkar\\_ponic.pdf](https://tspace.library.utoronto.ca/bitstream/1807/27218/1/10.1_jategaonkar_ponic.pdf)
- Johansen, H., Sanmartin, C. & Longitudinal Health and Administrative Data Initiative (LHAD) Research Team. (2011). *Mental comorbidity and its contribution to increased use of acute care hospital services*. Retrieved from

<http://www.statcan.gc.ca/pub/82-622-x/82-622-x2011006-eng.pdf>

Kerkorian, D., McKay, M., & Bannon, W. M. (2006). Seeking help a second time: Parents'/Caregivers' characterizations of previous experiences with mental health services for their children and perception of barriers to future use. *American Journal of Orthopsychiatry*, 76(2), 161-166.

Kirby, M. J. L., & Keon, W. J. (2006, May). *Out of the shadows at last: Transforming mental health, mental illness and addiction services in Canada*. Retrieved from <http://www.parl.gc.ca/Content/SEN/Committee/391/soci/rep/pdf/rep02may06part1-e.pdf>

Kirby, M. J. L., & Keon, W. J. (2004a, November). *Interim report on mental health, mental illness and addiction: Mental health policies and programs in selected countries*.

Retrieved from <http://www.mooddisorderscanada.ca/documents/Publications>

Kirby, M. J. L., & Keon, W. J. (2004b, November). Interim report on mental health, mental illness and addiction: Mental health, mental illness and addiction: Issues and options for Canada. Retrieved from <http://www.mooddisorderscanada.ca/documents/Publications>

Kirby, S. L., Greaves, L., & Reid, C. (2006). *Experience, research, social change: Methods beyond the mainstream* (2nd ed.). Peterborough, Canada: Broadview Press.

Klein, S., & Pulkingham, J., Pausel, S., Plancke, K., Smith, J., Sookraj, D., Vu, T., Wallace, B. & Worton, J. (2008a). *Living on welfare in BC: Experiences of longer-term "expected to work" recipients. Summary*. Available from Policy Alternatives: <https://www.policyalternatives.ca>

Klein, S., Griffin Cohen, M., Garner, T., Ivanova, I., Lee, M., Wallace, B., & Young, M. (2008b).

*A poverty reduction plan for BC: Summary.* Available from Policy Alternatives:

<https://www.policyalternatives.ca>

Knaak, S., & Patten, S. (2014). *Building and delivering successful anti-stigma programs for*

*healthcare providers: Results of a qualitative study.* Available from Mental Health

Commission of Canada: <http://www.mentalhealthcommission.ca>

Krueger, R. A. (1988). *Focus groups: A practical guide for applied research.* CA, Thousand

Oaks: Sage.

Lauritzen, C., & Reedtz, C. (2015). Knowledge transfer in the field of parental mental illness:

Objectives, effective strategies, indicators of success, and sustainability. *International*

*Journal of Mental Health Systems, 9(6), 1-8.*

Lees, R., Blume, D., Brindamour, L., Chovil, N., Gryba, H., Macnaughton, E., & Van

Volkinburgh, S. (2002). *Supporting families with parental mental illness: A*

*community education and development workshop.* Retrieved from

[http://www.mcf.gov.bc.ca/mental\\_health/pdf/supporting\\_families1.pdf](http://www.mcf.gov.bc.ca/mental_health/pdf/supporting_families1.pdf)

*Legal Services Society* Web site. (2015). Retrieved October 10, from

<http://www.familylaw.lss.bc.ca/>

LeFrancois, B. A. (2012). Distressed fathers and their children: A review of the literature.

*International Journal of Social Psychiatry, 58(2), 123-130.*

doi: 10.1177/0020764010387478

Lie, Gwat-Yong, & Este, D. (1999). *Professional social service delivery in a multicultural world.*

Available from ProQuest Ebrary: <http://site.ebrary.com.ezproxy.library.uvic.ca>

Linhorst, D. (2002). A review of the use and potential of focus groups in social work research. *Qualitative Social Work, 1*(2), 208-228. doi: 10.1177/1473325002001002620

MacKay, W., & Kim, N. (2009, February). *Adding social condition to the Canadian Human Rights Act.* Available from Canadian Health Research Council: [http://www.chrc-ccdp.ca/sites/default/files/sc\\_eng\\_1.pdf](http://www.chrc-ccdp.ca/sites/default/files/sc_eng_1.pdf)

Manning, A. R. (2009). Bridging the gap from availability to accessibility: Providing health and mental health services in schools. *Journal of Evidence-Based Social Work, 6*, 40-57. doi: 10.1080/15433710802633411

Marsh, D. T. (2000). Personal accounts of consumer/survivors: Insights and implications. *Journal of Clinical Psychology/In Session: Psychotherapy in Practice, 56*(11), 1447-1457.

Marsh, D. T. (2009). Parental mental illness: Issues in custody determinations. *American Journal of Family Law, 23*(1), 28-36.

Maybery, D., & Reupert, A. (2009). Parental mental illness: a review of barriers and issues for working with families and children. *Journal of Psychiatric and Mental Health Nursing, 16*, 784-791. doi: 10.111/j.1365-2850.2009.01456.x

Mensah, F. K., & Kiernan, K. E. (2010). Parents' mental health and children's cognitive and social development. *Social Psychiatry and Psychiatric Epidemiology, 45*, 1023-1035. doi: 10.1007/s00127-009-0137-y

Mental Health Commission of Canada [MHCC], (2012). *Changing directions, changing lives: The mental health strategy for Canada*. Retrieved from

<http://strategy.mentalhealthcommission.ca/pdf/strategy-text-en.pdf>

MHCC. (2013a). *Stigma, discrimination and PWLE knowledge: Discussion report*. Available from <http://www.mentalhealthcommission.ca>

MHCC. (2013b). School-based mental health in Canada: A final report. Available from <http://www.mentalhealthcommission.ca>

MHCC. (2013c). *Open Minds: Interim report*. Available from <http://www.mentalhealthcommission.ca>

MHCC. (2014). *National final report: Cross-site At Home/Chez Soi project*. Available from The Homeless Hub: <http://homelesshub.ca>

Metro Vancouver. (2015). *Housing data book*. Available from <http://www.metrovancouver.org>

Mikkonen, J., & Raphael, D. (2010). *The social determinants of health: The Canadian facts*. Retrieved from [http://www.thecanadianfacts.org/the\\_canadian\\_facts.pdf](http://www.thecanadianfacts.org/the_canadian_facts.pdf)

Min Park, J., Solomon, P., & Mandell, D. S. (2006). Involvement in the child welfare system among mothers with serious mental illness. *Psychiatric Services, 57*(4), 493-497.

Ministry of Children and Family Development (MCFD). (n.d.). Budget. Retrieved from [http://www.mcf.gov.bc.ca/about\\_us/budget.htm](http://www.mcf.gov.bc.ca/about_us/budget.htm)

MCFD (2013). *2013/14 - 2015/16 services plan*. Retrieved from <http://www.bcbudget.gov.bc.ca/2013/sp/pdf/ministry/cfd.pdf>

- Ministry of Health Services, & Ministry of Children and Family Development. (2010). *Healthy minds, healthy people: A ten-year plan to address mental health and substance use in BC.* Available from <http://www.health.gov.bc.ca/library/publications>
- Ministry of Social Development and Social Innovation (MSD). (2007). *BC Employment and Assistance Rate Tables.* Retrieved from <http://www.sdsi.gov.bc.ca/mhr/rates.htm>
- Mordoch, E., & Hall, W. A. (2002). Children living with a parent who has a mental illness: A critical analysis of the literature and research implications. *Archives of Psychiatric Nursing*, 16(5), 208-216.
- Morrow, M., Frischmuth, S., & Johnson, A. (2006). *Community-based mental health services in BC: Changes to income, employment and housing supports.* Available from Policy Alternatives: <http://www.policyalternatives.ca>
- Morrow, C. E., Mansoor, E., Hanson, K. L., Vogel, A. L., Rose-Jacobs, R., Seval Genatossio, C., Windham, A., & Bandstra, E. S. (2009). The Starting Early Starting Smart integrated services model: Improving access to behavioural health services in the paediatric health care setting for at-risk families with young children. *Journal of Child and Family Studies*, 19, 42-56. doi: 10.1007/s10826-009-9280-z
- Mowbray, C. T., Oyserman, D., & Ross, S. (1995). Parenting and the significance of children for women with a serious mental illness. *The Journal of Mental Health Administration*, 22(2), 189-200.
- Mowbray, C. T., Nicholson, J., & Bellamy, C. D. (2003). Psychosocial rehabilitation service needs of women. *Psychiatric Rehabilitation Journal*, 27(2), 104-113. doi: 10.1037/1541-1559.1.1.5

- Mowbray, C. T. & Mowbray, O. P. (2006). Psychosocial outcomes of adult children of mothers with depression and bipolar disorder. *Journal of Emotional and Behavioural Disorders, 14*(3), 130-142. doi: 10.1177/10634266060140030101
- Mueser, K. T., & Fox, L. (2002). A family intervention program for dual disorders. *Community Mental Health Journal, 38*(3), 253-270.
- Mulder, P., Jackson, R., & Jarvis, S. (2010). Services in rural areas. In B. Lubotsky Levin and A. Becker (Eds.), *A public health perspective of women's mental health*. Retrieved from Springer:  
[http://link.springer.com.ezproxy.library.uvic.ca/chapter/10.1007/978-1-4419-1526-9\\_16](http://link.springer.com.ezproxy.library.uvic.ca/chapter/10.1007/978-1-4419-1526-9_16)
- National Collaborating Centre for Determinants of Health. (2011, March). *Integrating social determinants of health and health equity into Canadian public health practice: Environmental Scan 2010*. Retrieved from  
[http://nccdh.ca/images/uploads/Environ\\_Report\\_EN.pdf](http://nccdh.ca/images/uploads/Environ_Report_EN.pdf)
- Nicholson, J., Sweeney, E. M., & Geller, J. L. (1998). Focus on women: Mothers with mental illness: I. The competing demands of parenting and living with mental illness. *Psychiatric Services, 49*(5), 635-642.
- Nicholson, J., Nason, M. W., Calabresi, A. O., & Yando, R. (1999). Fathers with severe mental illness: Characteristics and comparisons. *American Journal of Orthopsychiatry, 69*(1), 134-141.
- Nicholson, J., Biebel, K., Hinden, B., Henry, A., & Stier, L. (2001). *Critical issues for parents with mental illness and their families*. Available from  
<http://escholarship.umassmed.edu>

- Nicholson, J., Biebel, K., Katz-Leavy, J., & Williams, V. (2004). Prevalence of parenthood in adults with mental illness: Implications for state and federal policymakers, programs and providers. In R. W. Manderscheid and M. J. Henderson (Eds.). *Mental health, United States, 2002* (Chapter 10). Retrieved from  
[http://escholarship.umassmed.edu/cgi/viewcontent.cgi?article=1148&context=psych\\_pp](http://escholarship.umassmed.edu/cgi/viewcontent.cgi?article=1148&context=psych_pp)
- Nicholson, J., Finkelstein, N., Williams, V., Thom, J., Noether, C., & DeVilbiss, M. (2006). A comparison of mothers with co-occurring disorders and histories of violence living or separated from minor children. *The Journal of Behavioural Health Services and Research, 33*(2), 225-243. doi: 10.1007/s11414-006-9015-5
- Nicholson, J., Albert, K., Gershenson, B., Williams, V., & Biebel, K. (2008). Family Options for parents with mental illnesses: A developmental, mixed methods pilot study. *Psychiatric Rehabilitation Journal, 33*(2), 98-105.
- Nicholson, J. (2009). Guest editorial: Building the evidence base for families living with parental mental illness. *Australian e-Journal for the Advancement of Mental Health, 8*(3), 222-226.
- Nicholson, J. (2010). Parenting and recovery for mothers with mental disorders. In B. Lubotsky Levin and A. Becker (Eds.), *A public health perspective of women's mental health*. Available from Springer: <http://link.springer.com>
- Ontario Ministry of Health and Long-Term Care. (2012). *Health Equity Impact Assessment Workbook*. Retrieved from  
<http://www.health.gov.on.ca/en/pro/programs/heia/docs/workbook.pdf>

Office of the Ombudsperson. (2009). *Last resort: Improving fairness and accountability in British Columbia's income assistance program*. (No. 45). Available from  
<https://www.bcombudsperson.ca>

Office of the Ombudsperson Web site. (2015a). Retrieved from  
<https://www.bcombudsperson.ca/about>

Office of the Ombudsperson. (2015b). *2014-2015 Annual report*. Available from  
<https://www.bcombudsperson.ca>

Office of the Ombudsperson. (2015c). *Last resort: Improving fairness and accountability in British Columbia's income assistance program*. (No. 45). *Update on status of recommendations*. Available from <https://www.bcombudsperson.ca>

Ogden, R. (2008). Risk. In L. M. Given, (Ed.), *The SAGE encyclopedia of qualitative research methods* (Risk). Retrieved from  
<http://www.stiba-malang.com/uploadbank/pustaka/RM/QUALITATIVE%20METHOD%20SAGE%20ENCY.pdf>

Organization for Economic Co-operation and Development (OECD). (n.d.). *Social protection and wellbeing: Income distribution and poverty*. Available at <http://stats.oecd.org/>

Padgett, D. K. (2008). *Qualitative methods in social work research* (2nd ed.). Thousand Oaks, CA: Sage.

Perera, D. N., Short, L., & Fernbacher, S. (2015). There's a lot to it: Being a mother and living with a mental illness. *Advances in Mental Health*, 12(3), 167-181.  
doi: 10.1080/18374905.2014.11081895.

- Pfefferle, S. G., & Spitznagel, E. L. (2009). Children's mental health service use and maternal mental health: A path analytic model. *Children and Youth Services Review*, 31(3), 378-382. doi: 10.1016/j.childyouth.2008.09.003
- Phipps, S. (2003). *The impact of poverty on health: A scan of research literature*. Retrieved from Canadian Institute for Health Information:  
[https://secure.cihi.ca/free\\_products/CPHIIImpactonPoverty\\_e.pdf](https://secure.cihi.ca/free_products/CPHIIImpactonPoverty_e.pdf)
- Public Health Agency of Canada (PHAC). (2013). *What makes Canadians healthy or unhealthy?* Retrieved on September 20, 2015 from  
<http://www.phac-aspc.gc.ca/ph-sp/determinants/determinants-eng.php#income>
- Pullmann, M. D., VanHooser, S. V., Hoffman, C., & Heflinger, C. A. (2010). Barriers to and supports of family participation in rural system of care for children with serious emotional problems. *Community Mental Health Journal*, 46(3), 211-220.
- Pumariega, A. J., Winters, N. C., & Huffine, C. (2003). The evolution of systems of care for children's mental health: Forty years of community child and adolescent psychiatry. *Community Mental Health Journal*, 39(5), 399-425.
- Randall, M. (1992). *Gathering rage: The failure of the 20th century revolutions to develop a feminist agenda*. New York, NY: Monthly Review.
- Rauktis, M. E., Feidler, K., & Wood, J. (1998). Focus groups, program evaluation and the mentally ill. *Journal of Health & Social Policy*, 10(2), 75-92.  
doi: 10.1300/J045v10n02\_06
- Rawls, J. (1999). *A theory of justice* (Revised ed.). Cambridge, MA: The Belknap Press.

Available from <http://www.univpgri-palembang.ac.id>

Reedtz, C., Martinussen, M., Jorgensen, F. W., Handegard, B. H., & Morch, W. T. (2011).

Parents seeking help in child rearing: Who are they and how do their children behave?

*Journal of Children's Services*, 6(4), 264-274. doi: 10.1108/17466661111190956

Reid, G. J., Evans, B., Brown, J. B., Cunningham, C. E., Lent, B., Neufeld, R.,

Vingilis, E., Zaric, G. (2006). *Help - I need somebody: The experiences of families seeking treatment for children with psychosocial problems and the impact of delayed or deferred treatment*. Available from [www.chrsf.ca](http://www.chrsf.ca)

Reid, G. J., Cunningham, C. E., Tobon, J. I., Evans, B., Stewart, M., Brown, J. B.,

Lent, B., ...Shanley, D. C. (2011). Help-seeking for children with mental health problems: Parents' efforts and experiences. *Administration and Policy in Mental Health and Mental Health Services Research*, 38(5), 384-397. doi: 10.1007/s10488-010-0325-9

Representative for Children and Youth (RCY) (2013, April). *Still waiting: First-hand*

*experiences with youth mental health services in BC*. Retrieved from

<http://www.rcybc.ca/Images/PDFs/Reports/RCY-CYMHreport-Apr2013.pdf>

RCY. (2014a). *Who cares? BC children with complex medical, psychological and developmental*

*needs and their families deserve better*. Available from <https://www.rcybc.ca>

RCY. (2014b). *Not fully invested: A follow-up report on the representative's past*

*recommendations to help vulnerable children in BC*. Available from <https://www.rcybc.ca>

Representative for Children and Youth Web site. (2015). Retrieved from

<https://www.rcybc.ca/about-us>

- Reupert, A., & Maybery, D. (2007). Families affected by parental mental illness: A multiperspective account of issues and interventions. *American Journal of Orthopsychiatry*, 77(3), 362-369. doi: 10.1037/0002-9432.77.3.362
- Reupert, A., Goodyear, M., Eddy, K., Alliston, C., Mason, P., Maybery, D., & Fudge E. (2009). Australian programs and workforce initiatives for children and their families where a parent has a mental illness. *Australian e-Journal for the Advancement of Mental Health*, 8(3), 277-285.
- Reupert, A., & Maybery, D. (2009). A 'snapshot' of Australian programs to support children and adolescents whose parents have a mental illness. *Psychiatric Rehabilitation Journal*, 33(2), 125-132.
- Reupert, A., & Maybery, D. (2011). Programs for parents with a mental illness. *Journal of Psychiatric and Mental Health Nursing*, 18, 257-264.  
doi: 10.1111/j.1365-2850.2010.01660.x
- Roberts, G., & Grimes, K. (2001, March 31). *Return on investment: Mental health promotion and mental illness prevention*. Retrieved from  
[https://secure.cihi.ca/free\\_products/roi\\_mental\\_health\\_report\\_en.pdf](https://secure.cihi.ca/free_products/roi_mental_health_report_en.pdf)
- Royal College of Psychiatrists (2011). *Parents as patients: Supporting the needs of patients who are parents and their children*. Retrieved from  
<http://www.sssft.nhs.uk/images/Safeguarding/Patients-as-Parents-CR164---Staff.pdf>
- Ross, D. (2003). *Policy approaches to address the impact of poverty on health: A scan of policy literature*. Retrieved from Canadian Institute for Health Information:  
[https://secure.cihi.ca/free\\_products/CPHIPolicyApproaches\\_e.pdf](https://secure.cihi.ca/free_products/CPHIPolicyApproaches_e.pdf)

- Say How, O., & Caron, A. (2008). Family-based psychoeducation for children and adolescents with mood disorders. *Journal of Child and Family Studies, 17*, 809-822. doi: 10.1007/s10826-008-9191-4
- Sayal, K., Tischler, V., Coope, C., Robotham, S., Ashworth, M., Day, C., Tylee, A., & Simonoff, E. (2010). Parental help-seeking in primary care for child and adolescent mental health concerns: *Qualitative study. British Journal of Psychiatry, 197*(6), 476-481. doi: 10.1192/bjp.bp.110.081448
- Shanley, D., Reid, G., & Evans, B. (2008). How parents seek help for children with mental health problems. *Administration and Policy in Mental Health and Mental Health Services Research, 35*(3), 135-146. doi: 10.1007/s10488-006-0107-6
- Sheehan, R. (2004). Partnership in mental health and child welfare: Social work responses to children living with parental mental illness. *Social Work in Health Care, 39*(3-4), 309-324. doi: 10.1300/J010v39n03\_06
- Sieppert, J., te Linde, J., & Rutherford, G. (2004). Poverty as a determinant of health: Capturing the voices of low-income Calgarians. *Canadian Review of Social Policy, 53*, 122-139.
- Smith, M. (2004). Parental mental health: Disruptions to parenting and outcomes for children. *Child and Family Social Work, 9*, 3-11.
- Snowdown, A., Schnarr, K., Hussein, A., & Alessi, C. (2012, November). *Measuring what matters: The cost vs. values of health care*. Retrieved from <http://sites.ivey.ca/healthinnovation/files/2012/11/White-Paper-Measuring-What-Matters.pdf>

- Sommers, V. (2007). Schizophrenia: The impact of parental illness on children. *British Journal of Social Work, 37*, 1319-1334.
- Sood, E. D., Mendez, J. L., & Kendall, P. C. (2012). Acculturation, religiosity, and ethnicity predict mothers' causal beliefs about separation anxiety disorder and preferences for help-seeking. *Journal of Cross-Cultural Psychology, 43*(3), 393-409. doi: 10.1177/0022022110389492
- Statistics Canada. (2002). *Canadian community health survey: Mental Health and well-being*. Retrieved from  
<http://www.statcan.gc.ca/pub/82-617-x/index-eng.htm>
- Statistics Canada. (2012). *Portrait of families and living arrangements in Canada: Families, households and marital status, 2011 census of population*. Available from  
<http://www12.statcan.gc.ca>
- Statistics Canada (2013). *Canadian community health survey: Mental health, 2012*. Retrieved from <http://www.statcan.gc.ca/daily-quotidien/130918/dq130918a-eng.pdf>
- Staudt, M., & Cherry, D. (2009). Mental health and substance use problems of parents involved with child welfare: Are services Offered and provided? *Psychiatric Services, 60*(1), 56-60.
- Strauss, A., & Corbin, J. M. (1998). *Basics of qualitative research: Techniques and Procedures for developing Grounded Theory*. Thousand Oaks, CA: Sage.
- Styron, T. H., Pruett, M. K., McMahon, T. J., & Davidson, L. (2002). Fathers with serious mental illnesses: A neglected group. *Psychiatric Rehabilitation Journal, 25*(3), 215-222.

Sui Mui, C., & Ying Suet Chau, H. (2010). Growing up with a parent with schizophrenia:

What children say they need. *Journal of Children's Services*, 5(4), 31-42.

doi: 10.5042/jcs.2010.0693

Sutcliffe, S., Snelling, S., & Lacle, S. (2010). *Intervention project draft final report:*

*Implementing local public health practices to reduce social inequities in health.* Available

from <http://nccdh.ca/resources/entry/10-promising-practices-guide>

Swanson, J., Herman, T., Cardinal, J., Chan, K., Cheena, C., & Morrison, T. (2014). *On the*

*brink: The DTES housing crisis.* Retrieved from Carnegie Community Action Project:

<https://ccapvancouver.files.wordpress.com/2015/03/on-the-brink-dtes-housing-crisis.pdf>

Swartz, H. A., Zuckoff, A., Frank, E., Spielvogle, H. N., Shear, M. K., Fleming, M. A. D.,

& Scott, J. (2006). An open-label trial of enhanced brief interpersonal psychotherapy in

depressed mothers whose children are receiving psychiatric treatment. *Depression and*

*Anxiety*, 23, 398-404. doi: 10.1002/da.20212

Thomas, L., & Kalucy, R. (2003). Parents with mental illness: Lacking motivation to parent.

*International Journal of Mental Health Nursing*, 12(2), 153-157.

Thornberg, R. (2012). Informed grounded theory. *Scandinavian Journal of Educational*

*Research*, 56(3), 243-245.

Tjepkema, M., Wilkins, R., & Long, A. (2013). Cause-specific mortality by income adequacy in

Canada: A 16-year follow-up study. *Health Reports*, 24(7), 14-22. Retrieved from

<http://www.statcan.gc.ca/pub/82-003-x/2013007/article/11852-eng.pdf>

Townsend, E. (1998). *Good intentions overruled: A critique of empowerment in the routine*

*organization of mental health services.* Retrieved from ProQuest ebrary:

<http://site.ebrary.com.ezproxy.library.uvic.ca/lib/uvic/detail.action?docID=10200903>

Trainor, J., Pomeroy, E., & Pape, B. (2004). *A framework for support: Third Edition*. Available from Canadian Mental Health Association:

<https://www.cmha.ca/public-policy/policy-statements/?offset=10>

Trocme, N., Fallon, B., MacLaurin, B., Sinha, V., Black, T., Fast, E., ...Holroyd, J. (2010).

*Canadian incidence study of reported child abuse and neglect, 2008: Major findings.*

Available from ProQuest Ebrary:

<http://site.ebrary.com.ezproxy.library.uvic.ca/lib/uvic/detail.action?docID=10434638>

Tsoukalas, S., & Roberts, P. (2002). *Legal aid eligibility and coverage in Canada*. Retrieved from [http://www.justice.gc.ca/eng/rp-pr/csj-sjc/jsp-sjp/rr03\\_la5-rr03\\_aj5/rr03\\_la5.pdf](http://www.justice.gc.ca/eng/rp-pr/csj-sjc/jsp-sjp/rr03_la5-rr03_aj5/rr03_la5.pdf)

Tweddle, A., Battle, K., & Torjman, S. (2013, December). *Canada social report: Welfare in Canada, 2012*. Retrieved from Caledon Institute of Social Policy:

<http://www.caledoninst.org/Publications/PDF/1031ENG.pdf>

UN Department of Economic and Social Affairs (DESA). (2006). *Social justice in an open world: The role of the United Nations*. Retrieved from

<http://www.un.org/esa/socdev/documents/ifs/SocialJustice.pdf>

UN General Assembly, *Universal Declaration of Human Rights*, 217 A (III) 10 December 1948. Retrieved from <http://www.un.org/en/documents/udhr/>

UN General Assembly, *Vienna Declaration and Programme of Action*, 12 July 1993 A/CONF.

157/23. Retrieved from <http://www.ohchr.org/EN/ProfessionalInterest/Pages/Vienna.aspx>

UN Office of the High Commissioner for Human Rights (OHCHR), *Fact Sheet No. 2 (Rev.1)*,

*The International Bill of Human Rights*, June 1996, No. 2 (Rev.1). Retrieved from

<http://www.ohchr.org/Documents/Publications/FactSheet2Rev.1en.pdf>

UN General Assembly, *Convention on the Rights of Persons with Disabilities*,

A/RES/61/106 (13 December 2006), available from

<http://www.un.org/disabilities/convention/conventionfull.shtml>

Urquhart, C., Jasiura, F., Arthur, E., Seymour, A., Dartnall, M., Beltgens, P., Poole, N...

Schmidt, R. (2013). *Trauma-informed practice guide*. Available from the BC Centre of Excellence for Women's Health:

[http://bccewh.bc.ca/wp-content/uploads/2012/05/2013\\_TIP-Guide.pdf](http://bccewh.bc.ca/wp-content/uploads/2012/05/2013_TIP-Guide.pdf)

van der Linden, J., Drukker, M., Gunther, N., Feron, F., & van Os, J. (2003). Children's mental health service use, neighbourhood socioeconomic deprivation, and social capital. *Social Psychiatry and Psychiatric Epidemiology*, 38, 507-514. doi: 10.1007/s00127-003-0665-9

Vancouver Coastal Health. (2013). Adult Mental Health Program. Retrieved from

[http://www.vch.ca/403/7676/?program\\_id=317](http://www.vch.ca/403/7676/?program_id=317)

Vostanis, P., Graves, A., Meltzer, H., Goodman, R., Jenkins, R., & Brugha, T. (2006).

Relationship between parental psychopathology, parenting strategies and child mental health: Findings from the GB national study. *Social Psychiatry and Psychiatric Epidemiology*, 41(7), 509-514.

Wallace, B., Klein, S., & Reitsma-Street, M. (2006). *Denied assistance: Closing the front door on welfare in BC*. Available from Policy Alternatives: <https://www.policyalternatives.ca>

Walling, D. P., & Marsh, D. T. (2000). Relapse prevention in serious mental illness. *New*

- Directions for Mental Health Services*, 88, 49-60.
- Walsh, J., Schofield, G., Harris, G., Vostanis, P., Oyebode, F., & Coulthard, H. (2007). Attachment and coping strategies in middle childhood of children whose mothers have a mental health problem: Implications for social work practice. *British Journal of Social Work*, 39, 81-98.
- Weisel Cullen, S., Matejkowski, J. C., Marcus, S. C., & Solomon, P. L. (2009). Maternal mental health and pediatric health care use among a national sample of Medicaid- and SCHIP-insured children. *Journal of Behavioural Health Services & Research*, 37(4), 443-460.
- Weissman, M. M., Pilowsky, D. J., Wickramaratne, P. J., Talati, A., Wisniewski, S. R., Fava, M., Hughes, C. W. ...Rush, A. J. (2006). Remissions in maternal depression and child psychopathology: A STAR\*D-child report. *Journal of American Medical Association*, 295(12), 1389-1398.
- Westad, C., & McConnell, D. (2012). Child welfare involvement of mothers with mental health issues. *Community Mental Health*, 48, 29-37. doi: 10.1007/s10597-011-9374-0
- Williamson, K. (2006). Research in constructivist frameworks using ethnographic techniques. *Library Trends*, 55(1), 83-101. doi: 10.1353/lib.2006.0054
- World Health Organization. (2013). *Mental health action plan 2013-2020*. Available from [http://www.who.int/mental\\_health/publications/action\\_plan/en/](http://www.who.int/mental_health/publications/action_plan/en/)
- Young, I. M. (1994). Punishment, treatment, empowerment: Three approaches to policy for pregnant addicts. *Feminist Studies*, 20(1), 32-57. doi: 10.2307/3178429

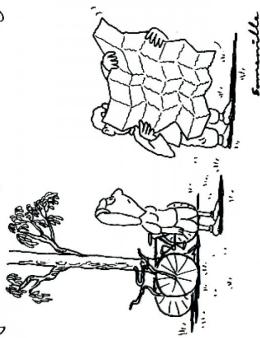
Yuh, J., Maloy, K. A., Kenney, K. A., & Reiss, D. (2006). General psychiatrists and their patients' children: Assessment and prevention. *Psychiatric Quarterly*, 77(2), 97-118. doi: 10.1077/s11126-006-9000-4

## Appendix A: Recruitment Poster

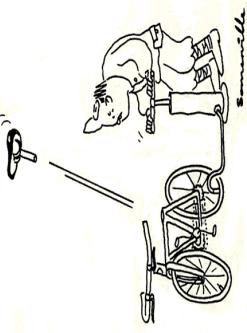
**You are invited to join a research study:**  
*Views and Experiences of Parents with Mental Illness of Parenting-specific Services*

PARENTING when you have a MENTAL ILLNESS can feel like an uphill climb!

Did you find the road to PARENTING SERVICES confusing or frustrating?...



Were there glitches or surprises?



Your experiences can help other parents with mental illness find their way to parenting services!

Sharing your views can help pave the road for needed changes!

### JOIN THIS STUDY!

THIS STUDY IS BEING DONE BY A MASTER'S STUDENT OF THE SCHOOL OF CHILD AND YOUTH CARE, UNIVERSITY OF VICTORIA



...Or was it better than you expected?

Have you ever asked for PARENTING HELP?



**Please contact Ginna Abramovitch, at 778-558-5509 or [ginna\\_abr@yahoo.ca](mailto:ginna_abr@yahoo.ca)**

(If you would like for Ginna to contact you, please arrange with [REDACTED] at the [REDACTED])

**You are invited to join a research study:**  
*Views and Experiences of Parents with Mental Illness of Parenting-specific Services*

**YOU CAN CHOOSE FROM  
ONE OR MORE ACTIVITIES:**

- **A GROUP DISCUSSION**
    - Meet other parents who have had similar experiences
    - Share your views
    - Be heard!
    - childcare and refreshments provided
  - **1:1 INTERVIEWS**
    - Opt to talk 1:1, in private
  - **COMMENT ON FINDINGS**
    - (If you were part of the group or 1:1 interview) you can be a consultant on the study!
- THE 'GOLDEN RULES' ARE:**
1. YOUR PARTICIPATION IS TOTALLY VOLUNTARY!
    - You can withdraw at any time!
  2. THIS STUDY IS NOT CONNECTED TO SERVICES YOU RECEIVE!
    - Your decision (to join or decline or withdraw) will not affect services to you IN ANY WAY!
  3. YOUR IDENTITY WILL BE PROTECTED and WHAT YOU SAY WILL BE KEPT IN STRICT CONFIDENCE!
    - You will know of any limitations to this before you join!!!
- A FEW MORE IMPORTANT THINGS:**
- **YOUR SAFETY AND COMFORT WILL ALWAYS COME FIRST!!!**
  - *I am NOT looking for information on SPECIFIC SERVICES you've had (no names, no details)*
  - *I will NOT be asking anyone else about you - only YOU!*
    - This includes Kristina Dixon or any other staff person at CMHA
  - *I am available at ANY TIME during the study for questions or to talk about concerns*
  - *If you have concerns about how you have been treated during this study, you can contact the Human Research Ethics Office at the University of Victoria at (250) 472-4545*

**Please contact **Ginna Abramovitch**, at **778-558-5509** or **ginna.abr@yahoo.ca****

(If you would like for Ginna to contact you, please arrange with [REDACTED] at the [REDACTED])

## Appendix B: Invitation Letter

### INVITATION TO:

#### VIEWS AND EXPERIENCES OF PARENTS WITH MENTAL ILLNESS OF PARENTING-SPECIFIC SERVICES

**YOU ARE INVITED** to participate in a research study led by Ginna Abramovitch, a graduate student of the School of Child and Youth Care, University of Victoria.

If you are a **parent with mental illness** and have had **parenting services\*** or **professional supports\*\*** for parenting issues (or you have tried to get services without success) you are invited to **SHARE YOUR VIEWS and EXPERIENCES!**

\*Parenting services include: workshops, groups, education, respite services

\*\*Professional supports include: professional advice or consultations with a doctor, social worker, or another professional

Your **EXPERTISE** on what it's like to contact parenting services (or try without success) can help service providers understand what's working, what's not, and what can be done better. Speak your mind and **BE HEARD!**

If you decide to participate, you can chose from these activities:

- a group discussion with other parents with mental illness
- 1:1 interview
- commenting on findings (if you participated in the group or 1:1 interviews)

Your participation is **TOTALLY VOLUNTARY!!!** You can easily withdraw from the study at any time. You will have many opportunities to ask questions, request supports or change your mind about what activity you would like to do.

Your **PRIVACY** will be protected and **CONFIDENTIALITY** maintained!!! \*\*\*

\*\*\*There are few limitations, of which you will be made fully aware before we start, and reminded of before each new activity, to make sure that you are **FULLY INFORMED!**

**JOIN THIS STUDY** to add to the collective voice of parents with mental illness!

- You will NOT be asked about specific services (no names, no details)
- No one else will be asked about you - JUST YOU! This includes [REDACTED] or any other staff person at the [REDACTED].
- Ginna will be available AT ANY TIME during the study for questions or to talk about any concerns you might have related to the study
- If you have concerns about how you are being treated in the study, you can contact the Human Research Ethics Office at University of Victoria at (205) 472-4545.

If you are interested in being a participant or if you have questions about the study please contact **Ginna at 778-558-5509 or ginna\_abr@yahoo.ca**

If you would like for Ginna to contact you, please arrange with [REDACTED], at the [REDACTED].

**THANK YOU!**

**Ginna Abramovitch at 778-558-5509 or ginna\_abr@yahoo.ca**

## Appendix C: Initial Screening Script

### INITIAL SCREENING SCRIPT

Hello. Is this...? My name is Ginna. I am the student that [agency representative] talked to you about. She let me know that you might be interested in the study I am doing. Are you available to talk with me for about 20 minutes or so? [Opportunity to reschedule to a more preferred time.]

...Great. Thank you so much. I really appreciate this. Do you mind if I start by giving you a brief introduction of what I hope to do?

The goal of this study is to speak with parents about their views and experiences of parenting services or professional supports for parenting. I am looking for your views on how well services (or professionals) reach out to parents with MI and how well they are able to meet their needs: what works, what doesn't and what can be better. My hope is that your experiences would help pave the way for change, to make it easier for all parents with MI to get services when they need them most. Does this sound like something you might be interested in?

...Terrific! I really appreciate your interest and your time.

I want to make sure that you are signing up knowing what to expect, so what I would like to do today is to give you an idea of what we would be doing together and how we would go about it. I will start by telling you some of the 'golden rules' that I will follow throughout the whole study (including today), and then go on to ask you a few brief questions about your experiences. I will also briefly talk about how we would work together during the study, to give you an idea of what to expect. The goal for today is to see if this study is a good fit for you. And please, don't hesitate to ask me any questions, at any time. Alright if we begin? ... O.K. Let's dive in then. This should take us about 15 minutes.

The first thing I want to let you know is that your participation must be absolutely voluntary. You can decide at any time that you don't wish to go any further and we will stop right then. This is 'golden rule' one - it applies to this conversation and anything else we do together as part of the research.

The second 'golden rule' is that this study is in no way connected to services you receive at the [agency], or anywhere else. Anything you say or do during the study will in no way affect the services you are getting now or any future services.

Do you have any questions so far? [Opportunity to discuss anticipated risks.]

As we go along, I will be typing your answers and comments (so you might hear a clicking sound - that's me typing on my computer). All of the notes I take on my computer I will store in password protected files to which only I will have access. Your contact information and any writ-

ten notes or papers are stored in a locked cabinet in my home. ONLY I WILL HAVE ACCESS TO THIS INFORMATION. *All* of the information I collect during the study will be securely stored and safely disposed of at the end of the study.

Does that sound alright with you? [Opportunity to clarify safeguards.]

The third ‘golden rule’ is that I will make every effort to protect your identity during and after the study. As part of this, I’m going to ask you to make up a name that I will use to track what you say without tying it to who you are in real life. Whatever name you choose, this will be the name I would use in all my notes, the entire time of the study, and in the reports on findings. If you would like for your real name to be used in the report on findings, to credit you to the things you have said, you are free to do that as well and we can discuss that when you are consenting to the study. Even in this case, though, I would ask you to choose another name that you are comfortable using while participating in the study.

You can think about how you would like to be identified in the study. For now, I will use a code to identify you in my notes.

[Opportunity to discuss anonymity concerns or desire to be connected to information being provided]

‘Golden rule’ #4 is anything you say, at any time, I will keep in strict confidence with one very important exception. The only time I would break our confidence is if your life or someone else’s was in danger. By law, I have to report information about a child whose life or wellbeing is in danger to the proper authorities. I would also contact emergency services if your life or someone else’s was in immediate danger. Even in these cases, I would only provide information to the proper authorities. And I would only give out information that had to do with ensuring your or another person’s safety (nothing else). This is very important for you to know, so that you know exactly what to expect at all times.

Do you have any questions about this? [Opportunity to discuss confidentiality and limits.]

THERE ARE A FEW OTHER POINTS I WANT TO MAKE SURE I COVER:

\* IF YOU DECIDE TO PARTICIPATE, I WILL NOT ASK YOU TO PROVIDE SPECIFICS ABOUT ANY SERVICE THAT YOU’VE HAD (THIS INCLUDES SERVICES WITH [the agency]) - SO YOU DO NOT NEED TO GIVE NAMES OR DETAILS OF SERVICES YOU’VE BEEN IN CONTACT WITH.

\* ALSO, I WILL NOT BE ASKING ANYONE ELSE ABOUT YOU - THIS INCLUDES [agency rep] OR ANY OTHER STAFF PERSON AT [the agency]. I WILL ONLY ASK YOU ABOUT YOUR EXPERIENCES OR ANYTHING ELSE.

\* I WILL BE AVAILABLE ANY TIME DURING THE STUDY BY PHONE OR EMAIL TO ANSWER ANY QUESTIONS YOU MIGHT HAVE ABOUT THE STUDY OR TO TALK ABOUT ANY CONCERNS YOU MIGHT HAVE RELATED TO THE STUDY.

\* AND IF YOU WANT TO TALK TO SOMEONE WHO IS COMPLETELY UNCONNECTED TO ME OR TO [agency rep] ABOUT HOW YOU HAVE BEEN TREATED DURING THE STUDY, YOU CAN CONTACT THE HUMAN RESEARCH ETHICS OFFICE AT THE UNIVERSITY OF VICTORIA. I CAN GIVE YOU THEIR CONTACT NOW IF YOU WISH... YOU CAN ALSO FIND IT ON THE POSTER AND INVITATION LETTER, AND IT WILL BE ON YOUR COPY OF THE CONSENT FORM FOR THE STUDY.

DO YOU HAVE ANY QUESTIONS ABOUT ANY OF THIS?

O.K. Now I have a few questions I would like to ask you.

I WANT TO LET YOU KNOW THAT BY ANSWERING THESE QUESTIONS YOU ARE NOT GIVING CONSENT TO BE PART OF THE STUDY. THE INFORMATION YOU GIVE ME TODAY WILL ONLY BE USED TO HELP ME UNDERSTAND HOW BEST TO ENSURE THAT YOU FEEL SAFE AND COMFORTABLE DURING THE STUDY, IF YOU DO DECIDE TO PARTICIPATE.

If you decide you don't want to participate, any information you give me today will not be used for any purpose. Alright if we proceed?

The first two questions are a double-check to make sure that we're on the same page.

Do you identify as a 'parent with MI'?

Do you have a child or children 18 years old or younger?

The next questions are about your experiences with services or professional supports related to parenting. Your answers will give me an idea about what kinds of experiences you've had with parenting services. Feel free to just answer 'yes' or 'no' for now.

Are you now receiving parenting services (like respite services, coaching, or parenting groups)?  
Have you had parenting services in the past?

Have you ever asked a professional for advice on parenting (like from a doctor, a counsellor, a mental health worker or someone else)?

Have you ever tried to get parenting services but haven't succeeded?

Have you ever been told that you have to contact parenting services?

Have you ever been offered services or professional supports for parenting which you declined?

Have you ever had negative experiences with services? ...positive?

[If no...]

Could you tell me a little about your experiences with parenting services or professional supports for parenting?

I very much look forward to hearing more about your experiences. So let me now briefly tell you how I plan to do that - this might give you a better idea of whether this study is something you are interested in doing.

To begin with, I am inviting a small group of parents to talk about their experiences with parenting services. This group will be at the Vancouver office of the [agency] on [street address], between 9am and 5pm. It will be on a weekday and will last about 2 hours. [the agency] has offered to help with transportation and childcare while you're in the group.

[the agency rep] WILL BE PART OF THIS GROUP TO OFFER SUPPORT TO PARENTS, AS NEEDED.

BECAUSE [the agency rep] WILL BE PART OF THIS GROUP, SHE WILL KNOW WHO WILL BE PARTICIPATING IN THE STUDY AND SHE WILL KNOW WHAT IS SAID IN THE GROUP. THE RULES ABOUT RESPECTING YOUR PRIVACY AND KEEPING WHAT YOU SAY IN STRICT CONFIDENCE APPLY AS EQUALLY TO ME AS TO [the agency rep]. SHE IS BOUND BY PROTOCOLS OF [the agency] AND BY PROFESSIONAL ETHICS TO MAINTAIN CONFIDENTIALITY.

Also, just so you know, [the agency rep] will not be collecting any information from the group and she will not use the information in any way outside of this study.

If you do not wish to be part of a group, but would still like to participate in the study, you have the option of doing a one-on-one interview with me.

After the group discussion (or the individual interview with me, if you choose this as an alternative to the group), I may ask you if you would like to do an additional one-on-one interview.

Please know that you are not obliged in any way to say 'yes' to any of these activities and I hope that you feel free to decline or withdraw from the study at any time. I would only ask that you let me know that this is your decision.

All individual interviews can be done at a time and place you prefer and each would last about 1 hour. You would also be compensated for your time with a small cash sum at the end of each interview.

The other things to note about the group discussion and interviews is that they will be audio recorded and I will take notes to help me understand the recording. So for example, I might note people's body language, actions, or interactions. These notes can help me remember the situation and better understand what is happening. Only I will have access to the recordings and notes.

Would you be interested in being part of the discussion group with other parents?

Is there anything that would make it easier for you to attend this group, like childcare or help with transportation?

Would you be interested in doing an interview with me one-on-one?

[Opportunity to identify preferences and barriers.]

The group discussion and individual interviews are the main ways in which I will collect information. My job will be to pull together information from all the parents to get at what's most important. At some point, I will ask you and the other parents if you are interested in taking a look at what I put together and comment on it. Your comments will help me stay on the right track.

...And that's pretty much the extent of what you might be asked to do, if you chose to go all the way to the end.

Do you have any questions about how the study will be done at this time?

[Opportunity to discuss process and participant expectations.]

My most important job will be to try to make sure that you and other parents feel safe and comfortable throughout this process. So it's very important that we can pinpoint anything that might stand in the way of that, right from the start and throughout the study. The next set of questions are there to help us do that. Please stop me and let me know if you are uncomfortable answering a question, or if you have questions for me. Alright if we proceed?

First of all, I have to be honest and say that there is no way that I can absolutely guarantee that you will not experience some part of the group discussion or interview as difficult or stressful. Some topics might be sensitive and might raise strong feelings. In my role as a researcher, there is a limit to how much support I can offer or to how helpful that support might be for you. So it is important that you have access to additional supports.

Are you connected with an adult mental health professional, someone who you see for *your* needs? And do you expect to continue to be able to contact this person over the next 6 months or longer?

[Opportunity to discuss the need for additional supports. Resources may be offered.]

Because things may change, I will check in with you about ongoing supports for you throughout the study.

It's also very important that you are able to tell me if you are feeling unsafe, distressed, or uncomfortable, because I may not be able to pick up on this on my own. I will check in with you about this each time we reconnect before an interview.

When we do check in, it will be important for you to let me know if you are not feeling well or you are feeling stressed. If your illness symptoms have changed or worsened, if you have added demands on your time, or if something else is increasing the stress in your life, doing an interview may simply be too much. If you are not feeling up to it at the time, we can try to schedule another time that will work better for you.

To check in, I will ask you the following questions:

- \* Are you still connected to an adult mental health professional for your needs?
- \* Have you had any recent changes in your illness or your life that might make it difficult for you to participate?
- \* On a scale of one to ten (one being very poor), how would you rate your ability to do the next activity?
- \* Keeping in mind that participating may be somewhat stressful or difficult, are you feeling up to going ahead?

I can imagine this feeling intrusive, but I want us to be as certain as possible that if we go forward, we aren't going ahead blindly. I don't want you to experience this study as stressful or to overwhelm you in any way. And if there is something that I can do to make it easier for you to participate, PLEASE LET ME KNOW.

That pretty well covers it, for the time being. Do you have any questions for me at this time?

So now the big question: Is this study something you would like to take part in?

Thank you so much. I really appreciate your interest in this. The next steps would be to set up a face-to-face meeting to sign a consent form and talk some more about the process. We can do this anywhere you like at whatever time works best for you. This next meeting should take about an hour and to show that I appreciate your time I will be able to offer you \$20 at the end of the next meeting.

## Appendix D: Initial Screening Questionnaire

### INITIAL SCREENING QUESTIONNAIRE

**DATE:**

**Participant Code:**

**REVIEWED:**

- Purpose
- Voluntarism
- No connection to current or future community services, including CMHA
- Handling and storing information (electronic and paper files)
- Protecting participant identity
- Confidentiality and limits

**PARTICIPANT CRITERIA:**

- 'parent with MI'
- have child or children 0-18 years

**Contact with parenting services:**

- |   |   |
|---|---|
| <input type="checkbox"/> currently receiving                | <input type="checkbox"/> have been mandated to services |
| <input type="checkbox"/> received in the past               | <input type="checkbox"/> have been offered by declined  |
| <input type="checkbox"/> have asked for professional advice | <input type="checkbox"/> negative experiences           |
| <input type="checkbox"/> attempted access without success   | <input type="checkbox"/> positive experiences           |

[Alternative]

*Could you please describe your experiences with parenting services/professional supports for parenting?*

**PREFERENCES:**

- focus group       individual interview

\* Is there anything that would make it easier for you to attend the focus group?

- transportation     childcare       other:

---

**PARTICIPANT CRITERIA FOR DATA GATHERING ACTIVITIES:**

- access to adult mental health supports/professional throughout the time of the study
  - reviewed ongoing 'check-in' questions
- 

**QUESTIONS (from participant):**

---

**TENTATIVE AGREEMENT:**

- YES
  - NO
- 

**FURTHER CONTACT:**

\* *Date, time, location of consent meeting documented on hard copy contact form*

*If participant request additional information/resources:*

- via email
- via mail
- in person

\* *Additional contact info documented on hard copy contact form*

## Appendix E: Participant Consent Form

### PARTICIPANT CONSENT FORM

---

**You are being invited to participate in a study entitled, *Views and Experiences of Parents with Mental Illness of Parenting-specific Services.***

This is a Master's level thesis led by Ginna Abramovitch, a student of the School of Child and Youth Care, University of Victoria. It is being supervised by Doctor Jessica Ball, faculty of the School of Child and Youth Care, University of Victoria. Jessica Ball can be reached by phone: 250-472-4128; fax: 250-721-7218; or email: [jball@uvic.ca](mailto:jball@uvic.ca)

If you have any questions about this study please do not hesitate to contact  
Ginna Abramovitch at [ginna\\_abr@yahoo.ca](mailto:ginna_abr@yahoo.ca) or 778-558-5509.

THIS STUDY HAS BEEN APPROVED BY THE UNIVERSITY OF VICTORIA HUMAN RESEARCH ETHICS REVIEW BOARD. IF YOU HAVE CONCERNS RELATED TO THIS STUDY, PLEASE CONTACT THE HUMAN RESEARCH ETHICS OFFICE AT [ethics@uvic.ca](mailto:ethics@uvic.ca) OR BY PHONE: 250-472-4545.

---

#### **PURPOSE**

---

##### ***What is this all about?***

This study aims to understand the views and experiences of parents with mental illness of parenting-specific services (or professional supports with parenting issues). I am interested in the process of engagement, including factors that helped and hindered parents from gaining access to services and factors that influenced a parent to maintain contact with services (or professionals) for support around parenting issues.

##### ***What do you hope to achieve?***

This study hopes to highlight how parents with mental illness view the ability of services to engage and support them. The increased understanding of the service needs of parents with mental illness and of factors of their engagement with services is intended to translate into targets for improvement in service structure and delivery.

The study offers parents with mental illness the opportunity to have their voices heard and to be part of the larger discussion between service providers, policy makers and others involved in the planning and delivery of services for parents with mental illness and their families.

---

## METHODS

---

**Participation in this study must be entirely voluntary.** You can chose one or more activities to complete and you can change your mind at any time. You can withdraw from the study altogether, *at any time, without penalty*. No explanation will be requested.

### ***What I am being asked to do?***

If you chose to do the study you may be asked to be part of a group discussion, to do one or more individual interviews, and to provide your comments on some of the preliminary findings.

The group discussion will be held at the █, █ Branch, during working hours. It will be approximately 2.5 hours in length with breaks and refreshments. You may be compensated for transportation to and from the group and childcare will be offered on site.

The individual interviews will be at a time and place you prefer and will be approximately 1 hour in length. You may also choose to do an individual interview as an alternative to the group discussion. You will receive a compensation of \$20 cash for your time at the end of each interview. This compensation will not be dependent on the length of the interview or on your continued participation in the research.

The group discussion and individual interviews will be audio recorded.

█ will take part in the group discussion in the role of timekeeper and support person to participants. In the role of timekeeper █ will record which participant spoke at which time in a tracking form.

█ will not be recording any information (aside from the timesheet) from the group and will not be using any information that you provide in the group in any way outside of the study.

In her role as support person to participants, █ can offer individual support during or after the group.

I will also take notes during or after the group discussion and individual interviews on the context of what is being said, to help me make sense of the audio recordings. The notes will record non-verbal communication, actions, interactions, and events.

You may also be asked to provide comments on preliminary findings from the first set of group discussions and interviews, if you participated in these. *If you are interested*, you would receive a '*initial findings report*' and '*comment survey*' to be filled out. Your comments can ensure that my interpretations are on track and make sense to you.

***Is any other information being collected AS PART OF THE STUDY?***

Throughout the study I will be attending a monthly meeting of community service providers, hosted by [REDACTED]. The purpose of attending this meeting is to gather up-to-date information on types of services for families affected by mental illness and on how these services are being offered. I will be looking for trends and patterns, such as service delivery options, innovative practices, service gaps and shortfalls. I will not be collecting or reporting information from this meeting, or any specific information about services (names or details), service providers, or persons who use the services.

The intent is to use the information gathered from the monthly meetings of local service providers with information gathered in group discussions and interviews with participants to gain a more complete picture of the context of services for parents with mental illness and their families.

Once the study is complete, I may present the findings to the local service providers attending this meeting, if there is interest. Participation in this monthly meeting may therefore offer an important opportunity to promote the intent of the study.

No one will be asked for information related to you or any other study participant. This includes [REDACTED] and other staff or volunteer persons at the [REDACTED] or any other non-profit, for-profit or government agency or individual professional.

***How will the information be recorded and stored?***

The audio recordings and notes from the group discussions and interviews, as well as comments on findings (collected through a comment survey) are the only means by which information related to you or any other participant in the study will be collected.

Only I will collect and record information in the study (aside from the timesheet filled out by [REDACTED] during the group discussion, which she will give to me at the end of each group).

The audio recordings will be done on my personal laptop (i.e., be in digital format). All the audio recordings and computer files will be password protected and stored on my personal laptop. I will have a backup external drive that will only be used for this purpose. This backup drive will be stored in a locked filing cabinet in my home, to which only I will have access.

All other notes in written format will be stored in a locked filing cabinet in my home, to which only I will have access.

***What will happen to the information I provide if I withdraw?***

If you do chose to withdraw, you will be asked at the time if you are willing to have the information already collected be part of the study. If you request that the information you

provided be withdrawn from the study, this request will be honoured without question. This information will not be used in the research in any way and will be securely stored and safely destroyed at the end of the study.

---

## ROLES

---

### ***Who is the lead on this study?***

I am the researcher (or ‘primary investigator’). My role is to collect information in a way that preserves the integrity of the source; to interpret that information in a meaningful way; and to present it in a way that facilitates its intended use. My primary responsibility is *to ensure that all participants feel safe and supported* throughout the study and appreciated for their generosity and expertise.

If you have any concerns or questions, I am available by phone or email at any time.

### ***What is the role of the [REDACTED]?***

This study is made possible through the partnership with the [REDACTED], [REDACTED] Branch ([REDACTED]). All participants are persons receiving services through [REDACTED]. [REDACTED] is offering space for the groups; compensation for (or assistance with) transportation to/from the groups; and childcare on site for the duration of each group.

[REDACTED] will receive a report on findings. This is considered an invaluable opportunity to promote the intent of the study as it allows for direct distribution of findings to local community service providers and policy makers.

### ***Who is [REDACTED] and what is her role in this?***

[REDACTED] is the [REDACTED] of the [REDACTED], [REDACTED] Branch. She is also the [REDACTED]. She is the first person to contact potential participants and introduce the study. She will act in a supportive role to participants throughout the study.

[REDACTED] is a vital member of the research team. Her first-hand knowledge of the needs of families who use [REDACTED] services, her expertise in program coordination, as well as her contacts with local service providers and policy makers are invaluable resources to the study.

[REDACTED] is bound by professional ethics and protocols to maintain in strict confidence any information about participants, including information obtained in the group discussion.

**Limits to confidentiality are discussed in detail in a later section of this form.**

### ***Are there any conflicts of interest?***

There will be no direct gains from this study to either [REDACTED] or to [REDACTED]. Gains for all parties are related to the intent of the study and therefore considered mutually beneficial.

**Your participation is in no way connected to you receiving services through [REDACTED] or any other government, non-profit or for-profit community agency or individual professional.**

**YOU ARE UNDER NO PRESSURE TO ACCEPT THE INVITATION OR TO CONTINUE TO VOLUNTEER YOUR TIME. YOUR PARTICIPATION MUST BE COMPLETELY VOLUNTARY.**

IF YOU HAVE CONCERNs RELATED TO THIS RESEARCH, PLEASE CONTACT THE HUMAN RESEARCH ETHICS OFFICE AT: ETHICS@UVIC.CA OR 250-472-4545.

---

## BENEFITS

---

***What benefits could I expect from participating in this study?***

The main benefit to you from this study is an opportunity to share your experiences with others - with your peers (in the group discussion) and with service providers and others (through distribution of findings). This study offers you the opportunity to have your views be heard.

Additional benefits to participants may include:

- \* recognition of personal strengths and self-advocacy skills
- \* increased feelings of inclusion and peer support through participation in group discussions, which may reduce the felt experiences of isolation and stigma
- \* opportunities to recognize the need for additional supports (as part of the ongoing support to participants throughout the research process)
- \* opportunity to access additional supports through services of the [REDACTED]
- \* information on resources and practical information regarding access and availability of services from peers (if participating in the focus group)

***What are some of the other benefits of my participation?***

The needs of parents with mental illness have been thus far ignored in Canadian mental health policy. Lack of attention in policy is likely to result in lack of dedicated resources for programs and services. **This study intends to bring attention to the need for development of policy and practice that supports parents with mental illness and their families.**

The research process is expected to increase the understanding of how to engage parents with mental illness in conversations that aim to tap into their experiences and ex-

pertise. The more such conversations happen, the more likely it is that the parents' voices will be heard by service providers and policy makers.

Your courage to speak your mind may encourage other parents with mental illness to exercise their individual and collective rights to have their needs met, in policy and in practice.

## INCONVENIENCES

### ***Will participating be a hassle?***

You may be slightly inconvenienced by participation in the study in the following ways:

- \* Devoting time out of your schedule to participation
- \* Traveling to/from the group discussion
  - \* Please note: compensation for travel expenses or assistance with transportation may be provided.
- \* Having to arrange for childcare for individual interviews, if you choose to do so
  - \* Please note that this is not a requirement for participating in the individual interview.
- \* If you chose to have the individual interviews at your home, the interview may interrupt your home/family routine
- \* If individual interviews are at a public location chosen by you, you may need to travel to/from this location

I would like to ensure, to the best of my ability, that your experience of participation is beneficial. If there is something that I can do to minimize the inconvenience of participation, please feel free to contact me to discuss this at any time throughout the study.

## RISKS

***What serious negative impacts could participating have on me or my family?  
What safeguards will you put in place?***

**PLEASE BE ASSURED THAT THE OVERALL LEVEL OF RISK TO YOU IS CONSIDERED MINIMAL.**

There are three possible types of risks to you as result of participating in this study. These are discussed below along with safeguards that will be in place to minimize the risks.

***Stress:***

There is a possibility that you may experience stress as a result of sharing or remembering negative experiences you may have had.

Your comfort in the study will always take precedence over research activities. You are encouraged to state your needs and request access to additional support throughout the study. I am available by phone or email at any time. As well, during and after the group discussion, both [REDACTED] and I will be available for one-on-one support, if this is needed.

To make sure that you are well-supported and fully aware of what you are being asked to do, I will check in with you before each new research activity. I will review the terms of consent, as these are described in this form and ask if you would still like to participate. I will also ask you a few questions to identify any changes to your life or health that may compromise your ability to participate.

If you are not feeling up to the task at the time, we can discuss alternatives or supports that may make it easier for you to participate.

**YOU CAN WITHDRAW FROM PARTICIPATION AT ANY TIME, WITHOUT PENALTY.**

*Stigma and loss of privacy:*

It is no secret that there is stigma attached to being a ‘parent with mental illness’ and that serious consequences can result to the parent and family if this information is made public.

**I WILL MAKE EVERY EFFORT TO PROTECT YOUR PRIVACY AND YOUR IDENTITY AS A RESEARCH PARTICIPANT.**

The following measures will be in place to protect your identity:

- \* Your name will not be identified in any of the audio recordings, notes, questionnaires, or comment surveys collected during the study. You will be identified by a code in the ‘initial screening questionnaire’ and in the ‘ongoing screening and consent form’. You are asked to choose a pseudonym: an alternative name you are comfortable using for the duration of the study that cannot be tied to your identity.
- \* Your name, contacts, pseudonym you chose and the code attached to you will be kept in a locked cabinet, to which only I will have access.
- \* All information recorded during the study will be kept under lock and key or in password protected files, to which only I will have access.
- \* Once this study has finished and the thesis has been approved, all information will be safely and permanently destroyed.
- \* Only I will be collecting or recording information from participants.
- \* You will be identified by your pseudonym in all reports on findings and presentations. Only if you specifically request to be identified by your real name in the reports on findings, will your identity be made public. If you do request to be identified, you will need

to sign a separate consent form, agreeing to release this researcher and all affiliated parties from responsibility to maintain anonymity and confidentiality on your behalf.

**If you decide to participate in the group discussion, there is an elevated risk that your identity as a 'parent with mental illness' or as a participant in the research may be made public.** I cannot guarantee that members of the group will keep all information in confidence. I also cannot guarantee that you will not be seen by members of the staff or the public when you come to the group, because the group is held at the [REDACTED] office of the [REDACTED], during regular working hours.

The following measures will be in place to minimize the risk to you:

- \* I will contact you before the group to remind you of the risks to ensure that you are still willing to participate or to offer an alternative (e.g. individual interview)
- \* I will instruct group members to keep personal identities of participants private and not to discuss what is said or done in the group with others. I will discuss the importance of maintaining confidentiality in detail, before the start of the group
- \* I will ensure that staff providing child minding during the group are only aware that you are there for a 'parent group'

[REDACTED] will have information about who is participating in the study. She will also take part in the group discussion and consequently will be privy to what happens in the group. [REDACTED] is bound by professional ethics and [REDACTED] protocols to maintain participant confidentiality.

Despite all these measures, it is possible that information you share in the group may be made public by another participant (knowingly or accidentally). If this occurs while the study is going on, please do not hesitate to contact me or [REDACTED] to talk about your concerns. In the case that the breach of confidence is discovered after the study has finished, you can contact [REDACTED] for support.

**All information you provide will be kept in strict confidence.** The only exceptions to this are discussed below.

*Risks associated with my PROFESSIONAL 'duty to report':*

There is a risk that *specific* information you provide will be reported to the proper authorities and there may be associated consequences to you or your family.

Please note that the research focus or questions asked during the group or individual interviews are not intended to elicit this kind of information.

There are three specific instances that warrant a breach in confidence:

1. If tell me about risk to *the life or welfare of a child*, I will report that information to the appropriate authorities (e.g., Ministry of Children and Family Development).
2. If you tell me (or if I have strong reasons to believe) that your life is in serious danger, I will discuss this with you directly and support you to access appropriate services or supports. If your life is in immediate danger, I will contact the police or ambulance.
3. If you tell me about serious or imminent danger to the life of another person, I will report this information to the police.

If you provide information that falls within the categories of ‘reportable information’ outlined above only the information directly related to the life and safety of a child or adult would be reported. This information would only be reported to the proper authorities — no one else.

If you provide information that falls within the categories of ‘reportable information’ outlined above during the group discussion, group members will be instructed to keep this information in confidence. However, it is impossible for me to guarantee this. Both [REDACTED] and I will be available to offer support to you in this instance.

If a breach in confidence is warranted, I will be available to offer support to you at the time and will offer to follow up with you thereafter.

---

## DISSEMINATION OF RESULTS

---

### ***What happens after all is said and done?***

First, as this study is a Masters’ level thesis, it will be presented to the academic committee at the University of Victoria and the written dissertation will be submitted for approval. It is also expected that findings will be presented in one or more academic conferences within the first two years of study completion and may be published in one or more academic journals. The conference presentations and the material sent for publication will exclude any information that may be used to identify participants.

A written report on the findings will be provided to the partnering agency ([REDACTED]). It is understood that the agency’s intent for the findings is to utilize them to support program development aimed at the needs of the local community. I may also present the findings to local service providers at a monthly meeting hosted by the [REDACTED]. No such presentation will be given to the agency staff (with the exception of [REDACTED] and leadership staff) to further minimize the chances that participants could be inadvertently identified.

*The ability to disseminate findings to the agency and to local service providers is considered vital to the intent of the study, as a means towards facilitating needed changes to the delivery of supports to parents with mental illness and their families and as a*

*means of offering parents with mental illness the opportunity to have a collective voice in this process.*

A final report will be given to all study participants. This report will outline the collective contributions of participants to the study topic and will invite participants to distribute the information to their peers and others, as they see fit.

If you would like to be identified by your real name in the reports on findings, so that you could be credited for the words and experiences you have shared, you will need to sign a separate consent form, agreeing to release this researcher and all affiliated parties from responsibility to maintain anonymity and confidentiality.

---

## CONTACTS

---

If you have any questions about this study please contact me, Ginna Abramovitch, at [ginna\\_abr@yahoo.ca](mailto:ginna_abr@yahoo.ca) or 778-558-5509 (private cell).

If you have any concerns regarding this study or your treatment as a participant, please contact the Human Research Ethics Office at: [ethics@uvic.ca](mailto:ethics@uvic.ca) or 250-472-4545.

---

## PREFERENCES

---

group discussion    interview (one or more)    review of initial findings

**You can change your preferences at any time without penalty.**

---

## SIGNATURES

---

*Your signature below indicates that you understand the terms of participation, as outlined in this form and that you have had the opportunity to have your questions answered by Ginna Abramovitch. Your signature also indicates that you are giving permission for what you say in the group discussion and interviews to be audio recorded.*

---

Participant's Name

Participant's Signature

Date

***You will be given a copy of this consent form and a copy will be taken for research records.***

---

**WITHDRAWAL OF CONSENT**

---

Date consent withdrawn: \_\_\_\_\_

Does the participant consent to use of data collected thus far?  yes  no

---

## Appendix F: Consent Discussion Script

### **CONSENT DISCUSSION SCRIPT**

#### **Informed Consent: What does that really mean?**

*Each person has the right to make decisions without stress or pressure. If you are feeling the stress of life demands, if you are feeling pressured to make a decision by someone, or you are experiencing symptoms of mental illness or ill-health you may regret any decisions you make under such circumstances.*

*To the best of my ability, I want to ensure that you do not regret the time you dedicate to this study. So it is very important to me that you feel that you can let me know if you do not wish to participate.*

*Your participation in this study is totally voluntary. There is absolutely no penalty to you from withdrawing and you can do this at any time, without giving an explanation. I will make sure that I check-in with you before each activity that we do together to give you the opportunity to let me know what you need - whether it's to withdraw completely or to reschedule for another time.*

*At this time, are you feeling alright to go ahead with this conversation?*

#### **Purpose:**

This study aims to understand the views and experiences of parents with mental illness (MI) of parenting-specific services (or professional supports with parenting issues). I am interested in your experiences as well as your views on, for example, whether and what was helpful and what services you were (or are) hoping to get, that you were not able to access.

#### **What do you hope to achieve?**

I am hoping the information we gather together will help service providers understand how to reach out to parents with mental illness and their families as well as how to best support them. I believe that one of the best ways to gain this understanding is to go straight to the experts: parents, like you.

I am also hoping that this study will be a venue for parents with MI to have their voices heard by local service providers and policy makers.

#### **Methods:**

**Your participation is entirely voluntary.**

I will ask you at the end of this form what activities you would like to be a part of, but this only gives me a rough idea of what you prefer: you can change your mind at any time.

You can also withdraw from the study altogether, *at any time, without penalty*. I will not ask you for an explanation, only that you let me know directly. I will ask you at the time if you are OK to have the information we already collected be part of the study, but you can decline my request without an explanation. If you participate, how much you participate, and what information goes into the study is up to you.

### ***What I am being asked to do?***

If you chose to do the study you may be asked to be part of a group discussion, to do one or more individual interviews, and to provide your comments on some of the initial findings.

The group discussion will be held at the [partnering agency], during working hours. It will be approximately 2.5 hours in length with breaks and refreshments. You may be compensated for transportation to and from the group or get a lift in the agency van. And there will be childcare on site.

You may be asked to do one or more individual interviews. You can also chose to do an interview instead of the group discussion. Each interview will be at a time and place you prefer and will be approximately 1 hour in length. You will receive a compensation of \$20 cash for your time at the end of each interview.

The group and interviews will be audio recorded. As well, [agency representative] will take part in the group discussion. She will be the timekeeper in the group: she will record who spoke at what time in a timesheet. She will then give me the timesheet, which will help me make sense of the audio recording.

[Agency rep] will not be recording any information (aside from the timesheet) from the group and will not be using any information that you provide in the group in any way outside of the study. [Agency rep] may also offer individual support to you during or after the group, if this is appropriate, or if you request it. The information that [the agency rep] will be privy to because of her attendance in the group may be used by her to provide support to you during the study. It will not be used for any other purpose.

I will also take notes to help me understand the context of what is being said and make sense of the audio recordings. The notes might record non-verbal communication (e.g., body language or facial expressions) or what is happening in the moment (e.g., actions, interactions, or events).

In addition to the group discussion and interviews you might be asked to comment on initial findings from the first set of discussions or interviews. If you are interested, I would send you a 'preliminary findings report' and a 'comment survey' to be filled out. If you chose to do this, you would act as an advisor on the study, letting me know if I am

on track. This is an important step in the study and your comments, if you chose to provide them, would be greatly appreciated.

***Is any other information being collected?***

The audio recordings and notes from the group discussions and interviews, as well as comments on findings (collected through a comment survey) are the only means by which information related to you or any other participant in the study will be collected.

Only I will collect and record information in the study (aside from the timesheet filled out by kristina during the group discussion, which she will give to me at the end of each group).

No one will be asked for information related to you or any other study participant. This includes [agency rep] and other staff or volunteer persons at the [partnering agency] or any other community or government agency.

Throughout the study, I will be part of a monthly group of community service providers, hosted by the [partnering agency]. Participating in this group will allow me to gain a better understanding of the state of services to families affected by mental illness, including how these services are being offered.

Participating in this group gives me a direct link to service providers, which may help me get the study findings across to those who need them.

**Roles of the researcher, the partnering agency, and agency representative:**

I want to make sure that we clearly define the roles of everyone involved: mine (the researcher), that of the agency representative, and of the partnering agency.

My main role is to collect, interpret, and distribute the information gathered from the study. My primary responsibility in that role is to ensure that everyone is safe and comfortable. If you have any concerns or questions throughout the study, you can contact me by phone or email at any time. My contact is in the consent form and also in the poster and letter describing the research.

I am partnering with [the agency rep] and the [agency] to be able to do both of my tasks to the best of my ability. The agency is giving space for the group discussions (at the [branch] office) and will assist participants with transportation and childcare so that they can attend the groups. This partnership offers an important opportunity to bring parents with MI to the table to talk about their experiences with parenting services and, once the study is done, to distribute the findings directly to local service providers and policy makers.

[Agency rep] is the [role in the agency]. She may be familiar to you. Her role is to introduce the research to new participants, as she did with you. She will be in the group dis-

cussion to offer any individual support to participants and also to keep track of who spoke at what time.

Even through [the agency rep] is ‘wearing two hats’ in the group: service provider and research team member, she is bound by professional ethics and agency protocols to keep all information completely confidential. This means that she cannot share information about you with me, or use information she obtains during the group in her role as service provider.

There are limits to confidentiality, with which both [the agency rep] and I must abide by — we will talk more about these in one of the next sections.

***Are there any possible conflicts of interest?***

There is one issue related to this partnership that I want to put out on the table.

I am partnering with [the agency] to be able to do this study, but it is also a place where you receive services. Also, [the agency rep] let me know that you might know her as someone who provided services to your family before. Because of this connection between this study, you and the agency (and [the agency rep]), there might be a chance that you are feeling pressure to participate. For example, you might be thinking that if you don’t accept, this might impact your relationship with [the agency rep] (or another staff person). Or, you might be thinking that if you decline, this will affect the services you receive from [the agency].

I want to make sure that you know that **this study is in NO WAY connected to current or future services through [this agency] or any other agency**. I will not ask you about specific services you are receiving at [the agency] and I will not ask about users of [the agency] services from any of the [the agency] staff, including [the agency representative].

**Your time is very much appreciated and there is absolutely no penalty to you if you decline.**

If at any point in time you feel that you cannot talk to me about something that is making you uncomfortable in the research, you can contact the Human Research Ethics Office at: [ethics@uvic.ca](mailto:ethics@uvic.ca) or 250-472-4545. Their contact is on this form. Their job is to ensure that I act in a way that respects your rights and freedoms and that I do what I promise to do. They have no investment in this research; they do not know me or I them; they are there to ensure that you are treated fairly. So, if you are feeling uncomfortable or unsafe, or have other concerns related to how you are being treated, please contact them.

**Benefits:**

The main benefit to you from this study is an opportunity to share your experiences with others, to have your voice heard and listened to.

My overall hope for the study results is that the local community of service providers and policy makers would gain understanding and insight to create the necessary changes.

Your courage to speak your mind may also encourage others to do the same. These conversations need to happen, and they need to happen more often. The collective rights of parents with mental illness need to be acknowledged in policy and respected in practice. Your voice, may be the first of many, that band together to make that happen.

### **Inconveniences:**

The consent form lists possible ways that you could be inconvenienced by the research.

If there is anything that either I or [the agency rep] can do (in partnership with [the agency]) that will decrease inconveniences and increase your comfort level, please let me know at any time throughout the study. We will do our best to accommodate.

### **Risks:**

#### **Stress:**

My primary responsibility is to ensure that all participants feel safe and comfortable throughout the research process. I will do my best to ensure this.

I cannot guarantee, however, that you won't experience some part of the group discussion or interview as stressful or difficult. This is certainly not the aim, but retelling or remembering bad experiences can bring up tension or strong emotions. I am always available to talk about how to best support you and [the agency rep] will be available if you need to talk about something in private, while the group is going on.

As I mentioned in our first conversation, it will be very important that you and I can talk about any supports that you might require, at any time throughout this study. The day before each scheduled activity I will contact you by phone and check in. I will do this to remind you of what's coming up and to make sure that you are still up to going ahead. I will also remind you that you can cancel or stop at any time (even in the middle of the interview or the group discussion) without any penalty to you. If you decide to pause, we can talk about other options, like rescheduling or doing another activity.

#### **Stigma and loss of privacy:**

It is no secret that there is stigma attached to being a 'parent with mental illness' and that serious consequences can result to the parent and family if this information is made public. **I will make every effort to protect your privacy and your identity as a research participant!**

**I will do this in the following ways:**

Your real name will not appear on any of the notes, recordings, or questionnaires used in the study. You will have a code and a 'fake' name to track what you say, without tying it to who you are in real life. I will ask you to choose a 'fake' name that you're comfortable with - I and others will refer to you by that name throughout the study.

All recorded information collected during the study will be kept under lock and key or in password protected files, to which only I will have access.

Even though [the agency rep] will be part of the group discussion and will know who is participating in the study, she will not be recording any information during the study or use anything she sees or hears during the group for any purpose other than providing support to you during the study. As I mentioned earlier, professional ethics and protocols of the [the agency] mandate that [the agency rep] strictly maintain participant confidentiality.

All identifying information: name, contacts, the 'fake' name you chose and codes attached to you will be kept in a separate file in a locked cabinet, to which only I will have access. The only two people that will know of your identity are [the agency rep] and I.

All information collected during the study will be securely stored until this thesis has been approved, at which time it will be safely and permanently destroyed.

You will be identified by the 'fake' name you chose in all reports on findings and presentations. If you would like to be identified by your real name in the reports on findings, you will need to sign a separate consent form, releasing me (and [the agency rep]) from responsibility to maintain your identity in private and keep what you say in confidence. (I will remind you about this option at the end of our conversation.)

**If you do decide to participate in the group, there is an increased risk to you that your identity as a 'parent with mental illness' and as a research participant will become public.** I cannot guarantee that members of the group will keep all information in confidence. And I cannot guarantee that you will not be seen by members of the staff or the public when you come to the [branch] office of the [agency], during regular working hours.

I will do my best to minimize this risk to you, including making sure that you are aware of the risks and can then make an informed decision of whether you want to participate or do an individual interview with me, as an alternative. I will also make sure that we discuss the importance of confidentiality in the group, before it begins, but there is no way for me to ensure that this will be respected by all members. You and other group participants would have to trust that you will honour each other's wishes. Also, I would only provide minimal information to the staff doing the child minding: that you are in a 'parent group'.

Even with all these measures in place, you should be aware that someone may (knowingly or accidentally) say something that they should have kept in confidence, which may in turn, have negative consequence for you. If this occurs while the study is going on, please do not hesitate to contact me (or [the agency rep]) to talk about your concerns. In the case that the breach of confidence is discovered much later, after the study has finished, you can contact [the agency rep].

I will keep all information you provide in strict confidence, with one very important exception: if a life is in danger - yours, a child's, or another person's. I WILL ONLY BREACH CONFIDENTIALITY TO PROTECT YOUR LIFE OR SOMEONE ELSE'S. The last risk to you from participation has to do with this exception. So let's talk about that in more detail.

*Risks associated with my 'duty to report':*

First of all, you need to know that in no way is the intent of this study to 'fish' for 'life or death' or any other 'reportable' information. You will not be asked questions about anything of the sort.

But you need to know that if you tell me about **significant risk to the safety of a child** I would have to contact the proper authorities. And if you tell me about **significant risk to the life of another adult**, I will have to contact the police. I will do my best to support you through this situation. The only information I would share in those cases is that which pertains to the child's or another person's safety and I would only share this with the proper authorities (no one else).

Also, if you tell me that your life is in serious danger, we will talk about this directly and I will do my best to support you contacting the right services. If I believe that your life is in immediate danger, I will contact the police or ambulance.

If you bring this type of information to the group, it is impossible for me to ensure that this information would be kept in confidence. If that happens, both [the agency rep] and I will be available to offer support.

**Dissemination of results: *Where will the information go after all is said and done?***

After the interviews are done, I will put together a final report. This report will be a condensed version of everyone's contributions. No one will be identified in this report, unless you specifically ask to be identified (in which case you would have to sign another form to confirm that this is what you would like). Otherwise, only the name you chose as your research name (your 'fake' name) will be used in the report to tie you to anything you say. Nothing that could be used to identify you, like names of services you've been in contact with, for example, will be used in the report.

This report will be given to you and all participants and you can decide to then give it to others to read, if you would like.

That report will also go to the [agency] to be distributed to the leadership staff for the purpose of service planning. It will not be available to the 'front line' staff who facilitate programs, with whom you may have direct contact while receiving services.

If there is interest, I may do a presentation about the study and what we were able to do together to local service providers at the monthly service provider group hosted by the [agency]. Distribution of information from the study to local service providers is one of the main intents for the study and this group my offer an opportunity to do just that.

I will also be presenting the study at my school, University of Victoria, as part of completing my degree. In this presentation, I will be talking to a panel of experts who will ask me questions about what we had done together and what sense I was able to make of the information we collected. I will also submit a written document on the study process and its results to be approved. This will be my 'thesis'.

In addition to all this, there is a good chance that I will present the study at one or more conferences or publish it in one or more journals.

Anything written or said about the study will include no information that could be used to identify you, including no mention of the name of [the agency] or any other services you have been in contact with. The only exception to this would be if you specifically ask to be credited to what you say.

IF YOU HAVE ANY QUESTIONS OR CONCERNS AT ANY TIME IN THE STUDY,  
PLEASE DO NOT HESITATE TO CALL OR EMAIL ME.

## Appendix G: Release of Identity Consent Form

### **PARTICIPANT CONSENT FORM: *Release of Identity***

---

**Please read this carefully. If the information in this form is unclear, please ask me any questions, before giving consent.**

**YOU ARE NOT BEING ASKED BY THIS RESEARCHER OR ANY AFFILIATED PARTIES TO HAVE YOUR IDENTITY RELEASED IN THE REPORT ON FINDINGS. THIS FORM SHOULD ONLY BE SIGNED IF YOU ARE REQUESTING TO HAVE YOUR IDENTITY (YOUR REAL NAME) BE ATTACHED TO THE INFORMATION YOU PROVIDE.**

---

I am a participant in the study entitled, *Views and experiences of parents with mental illness of parenting-specific services*. I do hereby consent to the use of  my first name only, or  my full name, for the purposes of quoting part of my comments obtained through the group discussion or an interview, to which I have already consented my participation.

I understand that by requesting that my real name be used for the purpose of quoting information, means that my identity will be known and listed in documents, including but not limited to: final reports, professional and academic publications, and presentations. The intended use for this information has been discussed with me.

I understand that by giving consent, this releases Ginna Abramovitch and any other parties affiliated with this study from responsibility to maintain anonymity and confidentiality regarding my participation in the study.

I understand that I can withdraw my consent to be identified in reports on findings at any time **PRIOR TO COMPLETION OF THE STUDY**. I may not withdraw my consent after completion of the study (i.e., once the findings have been reported).

### **CONTACTS**

---

If you have any questions about this study please contact me, Ginna Abramovitch, at [gin-na\\_abr@yahoo.ca](mailto:gin-na_abr@yahoo.ca) or 778-558-5509 (private cell). If you have any concerns regarding this study or your treatment as a participant, please contact the Human Research Ethics Office at: [ethics@uvic.ca](mailto:ethics@uvic.ca) or 250-472-4545.

### **SIGNATURES**

---

Your signature below indicates that you understand the terms of consent, as outlined in this form and that you have had the opportunity to have your questions answered by Ginna Abramovitch.

Participant's Name

Participant's Signature

Date

*You will be given a copy of this consent form and the original will be kept for research records.*

**WITHDRAWAL OF CONSENT**

---

Date consent withdrawn: \_\_\_\_\_

## Appendix H: Ongoing Screening and Consent Form

### ONGOING SCREENING AND CONSENT FORM

---

**DATE:**
**Participant Code:**
**Date of next activity:**
**Type of next activity:**       group discussion       interview
 
**TERMS OF CONSENT REVIEWED:**

**Purpose and Intent**

*The goal of this study is to engage parents with mental illness around their expertise related to the use of parenting-specific services. The intent for the results is to facilitate needed changes to the delivery of services to parents with mental illness and their families and to offer parents with mental illness the opportunity to have a collective voice in this process.*

**Voluntarism**

*Your participation in this study is entirely voluntary. You can withdraw at any time, without penalty or explanation. If you request that the information you provide not be used, your request will be honoured without question.*

**No connection to current or future receipt of services**

*Your participation is in no way connected to you receiving services through CMHA or any other government, non-profit or for-profit community agency.*

**There may be inconveniences or risks to you as a result of participation**

*You may experience some parts of the study as stressful.*

*You may experience stigma or loss of privacy, if your identity as a 'parent with mental illness' or as a research participant is made public. Your anonymity and confidentiality cannot be guaranteed, if you participate in the group discussion. If you report information about significant risks to the life or welfare of a child, or if you report information about a significant risk to the life of another person this information will be reported to the proper authorities. If your life is in immediate danger, I will contact the police or ambulance.*

**There are safeguards in place to minimize the risks to you**

*Your comfort and safety in the study will always take precedence over gathering information.*

*I will check-in with you before each new activity to ensure that you have an opportunity to state your needs, including an opportunity to withdraw.*

*Your identity will be protected. You will not be identified by name in any of the information collected in the course of the study or in the report on findings (unless you specifically request this). All information will be securely stored and safely disposed of at the end of the study.*

**Dissemination of results**

*Results will be disseminated in a way that protects your identity (unless you specifically request otherwise) and promotes the intent of this study.*

---

**Do you have any questions for me about the next activity or anything else regarding this study?**

---

**PARTICIPANT CRITERIA FOR DATA GATHERING ACTIVITIES:**

current access to adult mental health supports/professional

Have you had any recent changes in your illness or your life that might make it difficult for you to participate?  yes       no

On a scale of 1 to 10 (one being 'very poor'), how would you rate your ability to manage doing the next activity?

1     2     3     4     5     6     7     8     9     10

Is there anything that would make it easier for you to participate (e.g. change in type of activity; change of date/time of activity)?

---

**ONGOING CONSENT:**

Keeping in mind that participating may be somewhat stressful or difficult, are you feeling up to going ahead?  yes       no\*

\* If 'no'... Would it be alright for me to contact you at a later date, when you are feeling able to participate?  yes\*\*       no

\*\*Date (or approximate) of follow-up contact:

**ADDITIONAL SUPPORT:**

Document type\* of support if any was offered or provided

\* e.g. resources, contact with existing services/supports, contact with emergency services

---

**IF PARTICIPANT HAS WITHDRAWN CONSENT, THIS IS DOCUMENTED IN THE ORIGINAL CONSENT FORM**

---

***Any information collected in this form will not be used to support the research questions and will be kept strictly confidential.***

## Appendix I: Phase II Individual Interview Questions

---

### **Phase II Individual Questions: Example 1 (April 2015)**

---

#### **Re: parent service classification**

How do child-oriented services support you as a parent?  
 What impact do child services have on the overall family wellbeing?  
 How do child services that do not deliver, or do not meet your expectations, affect you as a parent? What are the consequences for your child, yourself, your family?  
 What services helped you respond to your child's mental health needs?  
 How does engagement with psychiatric services (for yourself) help you in your role as a parent?  
 Do you think of involvement with the Ministry as a 'parenting service'?  
 What is the difference between Ministry services and other parenting services based in the community?  
 What would be an ideal service context for provision of parenting services? (e.g. MCFD, CYMH, family service organizations, youth service organizations, schools)  
 Should parenting services be part of a continuum of services for the family? What would be the advantage of this way of offering parenting services?  
 What services have been instrumental in transforming (or lessening) the challenges of being a parent with mental illness over time?

#### **Re: process of "involvement with the Ministry"**

*[Re: enlisting the help of an outside SW to help you through the intake process; doing the research; having an understanding of what to expect]*  
 Could you describe your initial interaction with the Ministry - how you first requested services?  
 What did you say? What was the initial response? reaction?  
 How did you make sense of this response?

#### *As time went on...*

*[Re: throwing them off track; not doing what they were expecting or being who they expected you to be; not fitting the typical case]*  
 How did you realize 'this is not the way they normally handle things'?  
 What is the "way they normally handle things"? What are their usual actions, the "process they normally use"?  
 How did knowing this impact your approach? What was their response in turn? How did you need them to respond to your initial request? What actions would have been most helpful?

\* *Prompt for question: there is an aspect of "their process" that relates to meeting the needs of parents that are requesting services before a crisis, that are acting preemptively to prevent an emergency*

How did you realize that there is this other aspect to “their process”? How would you describe this other aspect, based on your observations?

Why, in your opinion, does this aspect get ignored?

*‘Dealing with’ “different branches”*

What differences did you find in the two “branches”: Family Preservation and Custody and Adoption with respect to overarching philosophy, operations, relationships with social workers?

*Changing social workers/providers*

\* *Prompt for question: this being the ‘standard’, the norm*

What is the impact of changing social workers on the process of getting the services you need?

How does the constant changing of provider affect you? your family?

*Retaining control, resisting, countering the ‘snowballing’ effect*

How do you resist in the process that is set up to take control away from you? How do you maintain control?

What professionals have supported you in this?

*Overall...*

What does it mean for you, being “involved with the Ministry”?

How would you define this process of ‘involvement’?

**Re: stigma, bias**

What are the differences between societal biases and professional biases on being a parent with mental illness? Do they reflect each other? Do professional biases have more of an impact?

What is the impact of professional bias, of being stigmatized by a service provider on the process of seeking services?

How much of the bias you encountered would you attribute to you being labeled ‘a parent with mental illness’?

What is the effect of having a label of a parent with mental illness on the process of accessing services through the Ministry?

If you had not encountered discrimination, how would that have affected your process?

What is needed to counter stigma within the helping community?

**Re: community services**

*Process of engagement*

Is there a typical process of accessing community services?

How is this process different from the process of access with the Ministry?

*Operations*

What are the main differences between how the Ministry operates and how community-based organization (e.g. contracted agencies) operate?

To what do you attribute these differences?

*Bias*

Do community services have the same kind of profiling as the Ministry?

What is the effect of having a label of a parent with MI on the process of accessing services through community organizations?

**Re: gap in services**

How do you make sense of this gap in services? Why is there, in your opinion, such a focus on reactive services, on emergency response?

What factors contribute to maintaining this gap, maintaining the status quo?

What is the impact of having few prevention and low-intervention resources on the system as a whole?

**Re: “flawed system”**

What is standing in the way of change?

Who should be responsible for initiating the change?

What accountability mechanisms need to be put in place to ensure that the ‘flaws’ do not become the standards of operation?

## **Phase II Individual Questions: Example 2 (May 2015)**

---

**Re: supporting families affected by mental illness:**

What supports are most important for your family?

What supports, in your opinion, are most important for families that have similar challenges?

What supports are most important to help a person heal?

What community supports are needed to help the family build a healthy future?

What can doctors do to support a parent dealing with mental illness?

What can social workers do?

Would it be helpful if more services reached out to you, rather than you having to find them?

When would that be most helpful? When would it not be helpful?

**Re: family and community support:**

When you do not have family support on a daily basis, is it even more important to have community support? Can community supports replace family support?

**Re: talking to providers:**

Do you think doctors - family doctors, psychiatrists, psychologists - know how difficult it is to talk about what you are dealing with?

What would happen if they understood this?

Do you think they would change the way they respond to you?

What would you hope the change would be?

Do you think that support persons - like social workers, counsellors, people who run parent groups - understand that mental illness can make you feel like you are alone? How can we help them understand?

What could social workers, counsellors, etc. do to show that they understand?

What can service providers - counsellors, social workers, doctors - do to make it easier to talk to them about what is going on inside, your feelings, your pain?

Does the kind of relationship that you have with a support person make a difference in whether you are able to talk to them more freely, more easily?

When you are talking to someone about your emotional pain, what response is most helpful?

**Re: relating:**

What factors influence the relationship between a parent and a service provider?

How does the relationship between a parent and a provider impact what services a parent receives?

How does the relationship between a parent and a service provider impact the parent's family?

What actions define an unhelpful, a negative relationship with a support person?

What are the consequences on the parent and family of a negative relationship?

What actions define a helpful, a positive relationship with a support person?

What are the consequences on the parent and family of a positive relationship with a service provider?

What does it mean 'to walk in someone's shoes'?

How do you 'go deeper' than trying to understand what the person has gone through?

## Appendix J: Initial Coding

### **Initial Coding: Example 1**

---

#### **Excerpt from individual interview [alternative to Focus Group] (October 2014)**

---

Section 13

*Participant:* Umm.. and I had, the entire time, like I've.. that I've dealt with Family Preservation Office and now in dealing with the Custody and Adoption office - cuz it's gotten that far

*Interviewer:* hmm-hmm. hmm-hmm.

S13\_Inicial coding

“its gotten that far”

*[parent process:]*

a process that's run away from you  
having no control  
getting farther than anticipated  
getting more than you bargain for  
losing negotiations  
not having power to arrest or reverse the direction of the process *[Memo! develop later]*

“dealing with”

*dealing with:* taking measures concerning someone or something, esp. with the intention of putting something right; coping with a difficult person or situation; having relations with a person, agency, organization

*[parent response:]*

taking measures  
putting it right (attempting to)  
acting based on your values, beliefs  
coping with, facing  
answering, responding  
engaging with, communicating, relating

*F/Up Qs:*

*What actions did you take in “dealing with” the Family Preservation Office?*

*What was their response?*

*How would you define your relationships with the social workers there?*

*What was the impact of these relationships on your overall assessment of their services?*

Family Preservation Office *[Memo: what's in a name?]*

## Initial Coding: Example 2

### Excerpt from Focus Group (November 2014)

*[This example contains references to memos and embedded early memos]*

#### Section 3

*Participant:* you know, basically told me to take my kid and take care of her or they would remove her from me. so, but the thing is, they didn't help me do anything. so, there was Ministry involvement.

#### S3\_Initial coding

"told me... or they would remove her"

*[service response:]*

being directive, blunt

giving directives: 'do your job as a parent', "take care of her"

not offering support or aid in the process

making threats

threatening removal of parenting rights *[Memo: rights vs. privileges]*

not helping

not doing "anything" to help

"Ministry involvement"

*[service process:]*

getting involved = threatening to remove child

**Memo:** "Ministry involvement" = threat to parenting rights [rights turn to privileges]

**Memo:** This sounds like 'they' [emergency response services] came as fast as they went. And then P1 was left alone to manage a complex set of circumstances, now with the added threat of parenting rights being removed.

*[service response:]*

appearing and disappearing *[follow up on this]*

"they didn't help me do anything"

*[parent process:]*

being left alone

'doing it yourself'

*[consequences of service response:]*

adding to the plate

adding stressors, complications

complicating

making it more difficult to manage

### **Initial Coding: Example 3**

---

#### **Excerpt from Focus Group (February 2015)**

*[This example contains embedded early Memos]*

Section 83

*Participant:* I think more parents- I was really [emphasis] fortunate and, my PWD was, I got it first time.

*K.Dixon:* hmm.

*Participant:* and because- and it was specifically, because [emphasis; knocking on table] of my doctor.

**Memo:**

*"I think more parents..."*

What is left unsaid? ‘...would be able to manage’ and/or ‘...would be able to recover faster’ ... and/or ‘would be able to keep their family together’ AND ‘if the system [bureaucracy] was set up to work *for* the parents instead of against them’ or ‘if more physicians/psychiatrists/first-responders knew how to work the system to the family’s advantage’ or ‘if more attention was paid to the importance of providing basic needs as a preventative measure for crises, illness, family breakdown, homelessness’ [each (or any combination) of which inevitably cost more than \$672 per month: the amount of disability assistance

*What would be the impact – short term and long term - on parents and families of a simplified process of application for disability assistance (i.e., easily accessible social benefits)? What actions are needed to implement and sustain a ‘working’ system of social benefits?*

*What defines a system that is working FOR families, rather than against them?*

S83\_Initial coding

*"I was really fortunate"*

*[parent process:]*

Being granted support – seeing this as being ‘lucky’, a ‘chance’, being granted a ‘privilege’ over others

*Spinning the wheel of fortune = applying for aid*

Little to No control

Leaving it to chance

Leaving your family’s future in the hands of others

Categorizing

Comparing ‘fortunate’ with ‘not-so-fortunate’ (or ‘not lucky enough’)

## Appendix K: Focused Coding

### Focused Coding: Example 1 (early stage)

#### Section from individual interview (November 2014)

*[This example shows use of Track Changes program, to develop and select codes]*

S4\_Focused coding [*track changes*]

*[Participant (P) is describing access limitations imposed by the court]*

What is clear is P's confusion between family court and Ministry services, including terms used to describe parenting rights (e.g. custody, guardianship, access).

Memo: These are competing powers?: family court (**FC**) and Ministry. **NO.** FC is it's own entity [different system; not system of parenting services]

...P makes the statement (earlier) that Ministry is "always number one". *[POWER: possible conditions of Ministry context]*

*who is in charge? who has the legal authority? how do parents make sense of this?*

*[service process:]*

little to no guidance from providers

confusing

giving unclear direction, explanation

Memo (reflecting on Participant's actions): *P does not seem confused about parent status but P's words are not clear: Is this part of the language barrier or is Ps confidence more about strength of character than understanding of the legal process?*

*\* maintaining confidence is key [links to parent process!]*

**[code] facing loss [condition of entry into system]**

losing rights! *[system process: removing rights and responsibilities]*

**[code] taking back control**

accessing legal services, legal advice

fighting for parental status

regaining rights

attempting to get custody of children

~~fighting with ex partner for custody of children~~

**[code] resisting:** insisting on competence: ability to understand and manage

managing a very complicated process *[links to doing it yourself - code: parent process]*

having confidence in own ability to understand and go through this process *[links to not giving up! - code: parent process]*

## Focused Coding: Example 2 (later stage)

### Excerpt from codes and categories: *working within the system - being exceptional*

[Example of developing codes, categories and links between them. Includes tacking changes, as used in the process of analysis. Letters and numbers in brackets denote speaker and location of statement.]

#### **“the right person for the job” [A5\_38] [*what does that mean?*]**

having experience and training in conjunction with being “perceptive” and “flexible” [A5]

“sensitive to our situation” [A5\_41]

#### **empathizing** [‘walking in another’s shoes’] **[code]**

#### **relating** [under ‘empathizing’]

#### **learning** [*DROP: not part of the parent’s process!*]

applying insight

upgrading skills [A5; A7]

#### **adapting**

- changing how you work [A5; A7]

#### **[working ethically!] [code]**

#### **reworking the framework** [A5; A7]

understanding the impact of framework and the “office” on your actions/responses [A5; A7]

changing the framework to suite your practice **[ethical practice]**

#### **being exceptional; RESISTING the system**

#### **fighting the current** [A5] [*? may be part of working ethically?*]

working with atypical processes [A5;A7]

e.g. resisting dominant frameworks, perspectives

#### **risking** [*working ethically!*]

going against policy [A5;A7]

‘circumventing’ the rules [A5; A7]

compromising professional position, integrity [A5; A7]

#### **WORKING ETHICALLY**

##### **not perfect - ethical!** [A5]

##### **working for the person** [vs. working for the system] [A5;A7;A4; A6]

doing what’s right [A5;A7;A4; A6; A1]

- doing right by the person [A5;A7;A4; A6]

working from a values perspective [vs. being policy-driven] [A1;V1,2]

- having best interests of the family at heart [A5;A7;A4; A6;A1;V1,2]

#### **working from a guiding ethic** [A4]

#### **accepting responsibility** [A5; A4; A7; A8; V1,2]

- for mistakes

- for inability to meet the request

- for system processes/impact of these

## Appendix L: Memo-writing

### Memo-writing: Example 1 (early stage)

#### Excerpt from Focus Group (November 2014)

##### Section 152

*Interviewer (I):* cuz there is a difference. you know when you're talking about about no changes in 20 years

*Participant1 (P1):* yah.

I: you know, and the same routine, the same process. \_\_\_\_[talking same time as B - bellow]

P1: well, yah. no I was shocked, right? you know, I'm I'm still shocked at, you know, watching, you know, as a child going through watching what my mom went through the social services, the supports, and this and that. and, you know, and for myself to go through it. [short breath out] like [another short breath out] what was the difference? we've

I: hm-hmm

P1: evolved how many years, like... where's the.. difference? and, in some ways, there have been so many cutbacks and yah [pause] oh, well, my mom had all this [emphasis], in a sense, but, changes nothing, you know.

##### Section 152\_Memo

What Belle is say here is that the “cutbacks” are not a positive development, but they did not affect the process: “changes nothing”. The key message from Belle is that nothing has changed in the process - it was experienced by her in the same way it was experienced by her mother 20 years ago. Cutbacks in services did not affect the experience of the process. This means that there is an independent variable that affects how the process of seeking and receiving supports is experienced. The amount of services or resources being funnelled into services has been reduced, but in Belle’s experience that “changes nothing”.

*What is at the core of how the process of seeking and receiving services is experienced?*

*F/up Qs:*

What has made the difference for you in experiencing this journey as painful or hopeful?

In your experiences with services what has made this journey more painful, more difficult? What has given you hope, helped motivate you, helped you not give up?

*In-context summary:*

This group has talked about the following elements of the process of engaging with services:

- the “implication of relationships” e.g. being judged or ridiculed leading to isolation, low self-worth and lack of motivation

- the importance of connection: e.g. connecting with others ‘in the same boat’; collaboration between services

- the value of the parent-child bond in motivating the parent to keep going, not to give up
- the importance of the approach to practice e.g. basing your actions/responses on your experiences; working from a value-based (ethical, moral) perspective
- the “human factor” e.g. understanding fear and loss; responding with compassion
- the importance of sharing your story to healing and to helping others heal: “shining a light”

### **Memo-writing: Example 2 (early stage)**

---

#### **Excerpt from Focus Group (February 2015)**

---

##### Section 106

*Participant (P3):* because, without [emphasis] housing, without good healthy food [emphasis on last 3 words], and without clothing on your back, how can you learn? how can you, take care of your family? how can you, go to work and not stress about it? how can you go home and, and, have a, a good mental [pause] you know, the m- the ability to take care ['take care': words through a laugh] of your family?

[affirming murmur in background]

P3: and raise [emphasis] your your kids in a way that's, helpful to society instead of just perpetuating mental illness [recording measure (RM) 2646] and trauma issues, and, having to deal with MCFD, and

*Interviewer (I): hm-hmm*

P3: you know? I mean, it's kinda s- big circle. how much of it is, learned behaviour and how much of it is [pause] actual, mental issues? you know? like, I get stressed because I'm hungry  
I: hm-hmm

P3: I get stressed because I'm, homeless or I'm going to be homeless, or, you know. so I'm freaking out on my kid - now my parenting issues are coming up.

I: hm-hmm

P3: you know, my parents had the same issues, so now my parents iss- my parenting issues are coming up. I'm yelling at my kid - is it because I'm tired? is it because I'm hungry? is it because my mental illness is rearing its ugly head? or is it because I have to try and figure out how to get him to school? or how I'm gonna feed him? and [RM 2670]

I: hm-hmm

P3: it just keeps going on and on and on

##### S106\_Memo

consequences of not having access to “necessities of life”:

not being able to learn

not benefitting from information being provided [applicable to various contexts: therapy, psychoeducation, referrals]

not having the ability to “take care of your family”  
 [fostering shame in response to own and societal expectations; creating anxiety about the child’s and family’s future; reflecting on perception of own abilities; triggering depression]  
 impacting concentration and productivity at work  
 [increasing potential of losing ‘face’ at work, being demoted, losing your job; fostering anxiety about this; increasing likelihood of taking more sick days, going off work on disability]  
 exacerbating “parenting issues” (i.e. poor parenting practices; increasing frequency and/or intensity of these)  
 parenting poorly (not up to own and/or societal expectations)

**“dealing with MCFD” *[code]***

[and the multitude of consequences that this entails for the family!  
 family breaking down  
 child’s mental health and development being impacted negatively

“perpetuating mental illness and trauma issues”

**perpetuating the degenerative cycle *[code]***

“it just keeps going on and on and on” - from generation to generation  
 creating generational impact  
 impacting present and future

*Questions raised by P3:*

How much of a family crisis is attributable to parental mental illness and how much to lack of access to basic needs?

How much of the child’s emotional and behavioural challenges (or his or her mental health and life challenges in adulthood) are attributable to parental mental illness and how much to the child’s family environment? [the answer to this ‘at least 50%’]

If a child is growing up in a family with multiple life stressors, most of which are related to not having access to basic needs, does the society that restricts access to basic needs not carry the responsibility for that child’s future?

**How much of our children’s future is directly dependent on our failure to provide basic needs to families?**

How much impact will our failures today have on our society tomorrow?

### Memo-writing: Example 3 (early stage)

#### Excerpt from Focus Group (November 2014)

##### Section 38

*Participant:* but, you know, it's it's only because, you're right [referring to Interviewer] I was on this little island, where, it's kinda like the blind leading the blind, right now. and its hard, you know. if you can-

##### S38\_Memo [parent process]

###### "I was on this little island"

In the conversation that Participant and I had before the group we talked about the idea that 'it takes a village to raise a child' - that it is impossible to 'do it all yourself'. The image of 'being on a little island' reflected the idea of being unsupported, of trying to 'do it all yourself'.

trying to do it all yourself is isolating  
isolating yourself and your family

- family of origin values can sometimes lead to isolation. In Participant's case, the drive to 'strive,' to 'try' to 'get there' made her feel like a failure, it made her limitations seem more pronounced to her, which made her push even harder to succeed. Pushing herself to 'be a good mom' meant 'doing it yourself,' which led to isolation. It led to blindness, like not being able to see the warning signs in your child and get her the help 'soon enough'.
  - pushing yourself, especially to do it yourself, can be blinding, [can lead you into a crisis]
- actions of family (e.g., judging, placing 'under a microscope') can also make you feel alone, which can lead to further isolation.
  - feeling alone leads to being alone
- being alone leads to feeling like a failure as a parent
- having little outside support can be "*like the blind leading the blind*"

###### "the blind leading the blind"

misdirecting, leading to a corner  
isolating, leading away from supports  
confusing, disorienting, frightening  
pointless, waisting effort, not concentrating energy on what would help

###### "I was on this little island"

not having access to help, especially in emergencies  
not developing relationships  
losing connections  
struggling to get to the 'mainland'

## Memo-writing: Example 4 (reflexive)

**From an individual interview (November 2014)**

### Section 18\_Memo (reflexive)

...this is Participant's (P) background (family history) ...and difficult to understand - I don't not want to pry into this, as this is unrelated to the study topic

I think P's agenda is becoming clear: P wants to be seen as a good spouse and parent and is describing the events with a focus on actions: attempts to manage and mend the situation

*my process:*

I am becoming frustrated in the interview, as there is a lot of information that is unrelated to the topic. This is bringing attention to my skills at asking questions. I am too ambiguous; unclear in what it is I am asking. This needs work. This is coming from my timidity... my insecurity in the researcher role. I am also being hyper-vigilant about my place in the word of these parents. I represent the 'system,' the 'provider' and I have power here... but this is not how I feel. I feel grateful, humbled, a novice, a child. I have to reconcile these two sides. I have to acknowledge and hold on to the power that is mine. Denying this is not helpful. I know this from experience. Knowing what I hold allows me to wield it for good. Denying it can be damaging.

...There is more here. This is about the provider-recipient relationship but also about the researcher-participant relationship. I need to figure out the difference. I can feel it, but it's difficult to put to words... It has to do with the level of trust that is given. I AM a provider. And I am NOT a provider. This reminds me of working for MCFD as a youth support/crisis response worker: I would routinely say 'not a SW' when knocking on people's doors. and then the door would open. there would still be apprehension but that was different from the fear or disdain or numbness [shutting down, shutting off]... that I saw in the responses of parents to SWs... where am I going with this? the difference in the power dynamic. the researcher-participant dynamic is different to me. there is more trust from the start of the relationship. there is more openness. more willingness to share. I am being invited into the lived experience of these parents. This is like being invited into their homes. I am a guest here. I must tread lightly and mindfully. I must respect their space. And honour their invitation.

Back to the question: how do I reconcile having power with feeling powerless?

...Maybe the key is to hold the tension between being powerful and being humble ...maybe the point is NOT to choose a side.

## Memo-writing: Example 5 (reflexive)

---

### Memo: resisting

---

*[coding:]*

responding to the context of ‘no choice’

responding to oppression (controlling, disempowering, powering over, removing rights, locking into a degenerative cycle/reinforcing dependence)

resisting the ‘current’ (processes that are acting on the parent)

standing ground!

*[reflection: parent process]*

The people that answered the call to participate in this project all expressed resistance; and this makes sense, considering the project objective. Even these people, however, gave clues to the reality of ‘keeping the fight alive’: strength is not invariable and sometimes there is little to no resistance left in you at the end of the day. While all of us are resisting oppression in some way (is this not part of being human?) The amount of ‘fight’ in each of us is different and ever-changing, depending on many factors.

*[reflection: process-response]*

The monolith shows no sign of weakening and that in itself is a deterrent to would-be revolutionists. This is an old oppressive tactic: make them believe that you are indestructible, omnipotent, eternal, a God and they will not challenge your dominance or your acquisition of wealth. It is undoubtedly difficult - and some would argue, pointless - to be an ant pushing at a wall. Yet the message from parent to parent is clear: you can’t give up. This call resounded throughout the interviews: “**you can’t give up!**” If for no one, but for your children, you must keep pushing.

*[as a provider]:*

We have to continue to fight; we must do more. United in responsibility to our children. Armed with experience. Sustained by hope. *How*, is the question. How do we do this? How do we, little ants, keep pushing?

*[as me]:*

would I be able to do what these parents do on a daily basis? would I be able to step into their shoes and walk a mile... two miles?... an entire lifetime?... would I give up? would I commit suicide? would I leave my child? would I be blamed?... you just can’t imagine this, until it is in front of you, or on top of you. so how can you judge? ...have I judged in the past? will I judge again? the experiences that these people have shared will remain with me. my hope is that I am changed by them, as a service provider and as a person.

## Memo-writing: Example 6 (later stage)

*[Letters and numbers in brackets denote speaker and location of statement.]*

### Memo: resisting, going against the grain [exceptional provider]

#### **going against the grain [A5;A7]**

working with atypical processes [resisting standardization]

resisting dominant frameworks [resisting socialization; dominant frameworks]

- not viewing the parent as 'the problem'
- focusing on solutions, rather than problems

#### **fighting the current [A5;A7] [coding: same as above; collapse]**

there are providers who resist the 'grain' of the framework

Both provider and recipient are oppressed by the system; both resist in similar ways...?

If this is so, the power hierarchy is not created by the provider and recreating it within the provider-recipient relationship is a choice. **[making difficult choices - ethical?]**

Undoubtedly, making this choice is an ongoing and difficult process. But knowing that you have this choice is liberating! It means that change is possible. Having the awareness of the extent of the influence of the system on the provider and the recipient - and on relationships between them - exposes the inner-machinery, making the monolith more vulnerable to being affected.

As well, the awareness of a shared struggle, of being '**in the same boat**' [A6] by the provider and the recipient opens up the **possibilities of true partnership**, of joined resistance, of working together to revolutionize the system. [A5]

*fighting for agency?*

*How do providers fight for agency in the system?*

#### **going against the grain: 'circumventing' protocol [A5; A7]**

= **having to compromise professional integrity** [A5; A7]

**risking!**

This speaks volumes about the system: offering no alternative but to 'circumvent' the rules

*What happens to those who openly counter protocol?*

### Memo-writing: Example 7 (later stage)

*[Letters and numbers in brackets denote speaker and location of statement.]*

#### Memo: who benefits from the system? whom does the system serve?

is the biased perspective the key? or are the conditions the key? (e.g. limited resources) conditions influence perspective: not matching needs to resources exacerbates poverty, mental illness, inability to care for the child, effectively creating “the lowest common denominator” [A5]. when conditions [cause of destitution] are not visible, the bias against the person is reinforced. this is especially true if the public perspective on how this country operates is ‘socialist’: providing equal opportunity to its citizens to succeed. from this perspective, the blame falls squarely on the person for allowing destitution, dependence, and illness to take hold. the person is viewed as a leech on the system supported by the money of the middle class. so it becomes OK to only give people a little, ‘because we’ve already given them a lot and they just keep coming back for more’. the government dependents are highly controlled and monitored, because they are seen as incapable, as needing strict guidance to ensure that the little bit they get isn’t squandered.

while the middle class supports (financially) the welfare system, they do not benefit from it. nor would they benefit from it if they became poor. those who depend on the system, do not benefit from it. people do not want to be poor, dependent, destitute, or ill. if the welfare system only serves to keep people in these conditions, it does not serve them. so who benefits from the system? whom does the system serve? in the answer to these questions lies the key to understanding how the system operates.

if those who benefit from the system are those who make money, then it is their individual and collective [national? global?] greed that gives rise to conditions that maintain the system.

perhaps ‘perspective’ is a rationalization mass marketed to the public. when the poor, the ill, the addicted are viewed as the ‘minority’, then it becomes OK if the government (seemingly) focuses their efforts on the ‘majority’: the middle class. The minority can be forgotten so long as the majority thrives?

we are extremely privileged in this this country, where most of us are comfortable enough to forget about the poor, the ill, the homeless, the starving. from the perspective of a person [A1] who came here as a child from a war-torn country, having survived two attempts to flee and then life in a refugee camp, having seen death and destruction at the hands of the government sworn to protect its people, this country is a haven. this country is a place where a child has equal opportunity - to other children of low to middle class families - to succeed in making a good life, to become a good person.

## Memo-writing: Example 8 (language in coding)

---

### **Memo: maintaining a hierarchy [code]**

*maintaining*: preserving, conserving, keeping, retaining, sustaining, perpetuating, prolonging, continuing; supporting, nurturing, feeding; affirming, avowing, asserting

#### **Processes:**

**oppressing, marginalizing [code?]**

**controlling [code]**

How do these relate to each other?

#### **oppressing [abusing power]**

*oppressing*: keeping (someone) in subservience and hardship, esp. by the unjust exercise of authority {subservient: less important, subordinate, prepared to obey unquestioningly}

*oppressing*: persecuting, abusing, maltreating, repressing, suppressing, subjugating, subduing, keeping down, depressing, making despondent, weighing down, dispiriting, discouraging, bringing down

#### **marginalizing [abusing power?]**

*marginalizing*: treating as insignificant, trivial; isolating, cutting off, shutting out, alienating; discriminating against, being biased against, treating unfairly, putting at a disadvantage; victimizing

\* When one is marginalized, one is oppressed. When one is oppressed, one is marginalized.

There is no discernible difference

**coding: chose one: MARGINALIZING**

#### **Key Processes: Marginalizing**

**Main operating process: [through which others are operationalized]**

#### **Controlling**

#### **controlling [exercising power]**

*controlling*: maintaining influence or authority over, being in charge of, commanding, ruling, governing; containing, regulating, keeping in check; restraining, repressing, limiting, restricting

For example, gating through the use of social status (SES) or racial profiling is a means of marginalizing. Furthermore, gating sub-divides those who enter the system into two arbitrary groups: ‘the haves’ [those that get access to services] and the ‘have nots’. When this division is based on SES or racial profiling, it reinforces societal stigma, prejudice, racism and other forms of discrimination.

Note: collapse the codes of Controlling and Powering over

**CONTROLLING: exercising power over the person who enters the system**

## Process of selecting and developing memos: Example 9

### From Memos on “the system”

*[Includes tacking changes, as used in the process of analysis. Letters and numbers in brackets denote speaker and location of statement.]*

Memo: processes - interrelationships [coding]

[rework; retain section on interrelatedness of processes]

\* Reinforcing chosen as the process of maintaining the system: strengthening structures and processes [DROPPED!]

\* Controlling chosen as the process of maintaining the relationship of the system to those who are part of the system [provider and parent] i.e. maintaining a hierarchy - focus on relationship of the system to the parent!!!—

**REWORK!!!—**

The top [system-wide] processes do not work in isolation; they interrelate with other processes, connecting them in a complex system. The processes through which Reinforcing is operationalized (e.g. standardizing, socializing) are a means of controlling the relationship between the system and the people within it. For example, profiling, is a process of standardizing, that is used in the process of gating access to services, as a means of controlling who is granted access to services. The outcome is marginalizing and maintaining dependence on the system.

Memo: regulating systems vs. controlling people

Gating, Triaging, Profiling = processes that begin as sub-processes of Regulating the system:

**profiling [A5;A7;A8]**

slotting each recipient into developed classifications [e.g. forms]

compiling a profile [a “type of person”] based on typical presentation/usual experiences using this profile to predict capabilities as well as needed intervention and approach

**triaging [A5;A7;A8]**

developing a system of responding to presenting needs: assessing needs; matching needs to service response; differentiating

**gating access to resources [A5;A6;A7;A8;B3] !!!**

developing a system of providing access to resources based on presenting need: matching needs to resources

- like the bicycle that is more than the sum of its parts, when these operations are fitted together into a system, the system begins a new relationship to the people.

- within a system these processes become a means of controlling people. this is reinforced by the condition of limited resources and the paternalistic perspective on those who depend on it.

*note on process of coding: separated profiling and triaging from gating and moved all to ‘response to conditions’*

## Process of selecting and developing memos: Example 10

### From memos on *Ministry process*

*[Includes tacking changes, as used in the process of analysis. Letters and numbers in brackets denote speaker and location of statement.]*

#### Memo: **Ministry processes: typical, atypical**

“normal process” [A5\_57]: **removing** the child

[framework: risk; actions: accessing risk, proving risk, etc.]

developing, **streamlining** “normal process” [A5\_57] **standardizing**

fast, efficient, gaining, **speed** momentum after removal (‘snowballing’) [A5\_4]

- “Getting them to come in and take your kid is easy.” [A5\_15]
- being efficient, quick [connects to system response]
- responding automatically [connects to system response]

#### Atypical processes: **[system response]**

> **not well developed; cuts off; does not connect parent to services [not easily]?**

“**a dead end** process [A5\_49]; “**no other options to go anywhere**” [A5\_49]

“while it’s not outside their process, it’s not a process they typically use” [A5]

[1] **strengthening families:** requesting services [A5\_12]; pre-emptive action by parent [A5\_12]

[2] **facilitating independence [supporting recovery]:** parent requesting a removal of CCO [A5]

- reversing a decision [difficult process; going against the flow] [A5\_17]

#### Memo: **profiling [drop: REPEATING: SYSTEMS]**

**profiling** [A5\_25] [forms, protocols aiding this process]

- creating a description of the person based on ‘typical’ presentation
- using this to decide level of intervention —> **predetermine service response**
- comparing those who enter the system to existing profile

#### **profiling [marginalizing]**

- profiling based on “extreme case”, “lowest common denominator” [A5]
- not seeing the individual

#### Memo: **profiling —> labelling [controlling] [COLLAPSE: SYSTEMS]**

##### **labelling** [A5\_38]—

- assigning a code, a name, or designation that corresponds to a set of predetermined actions/interventions

> some labels stick better than others e.g. aggressive, unsafe, resistant, uncooperative, oppositional, emotionally unstable; also: schizophrenic, manic depressive, bipolar, PD

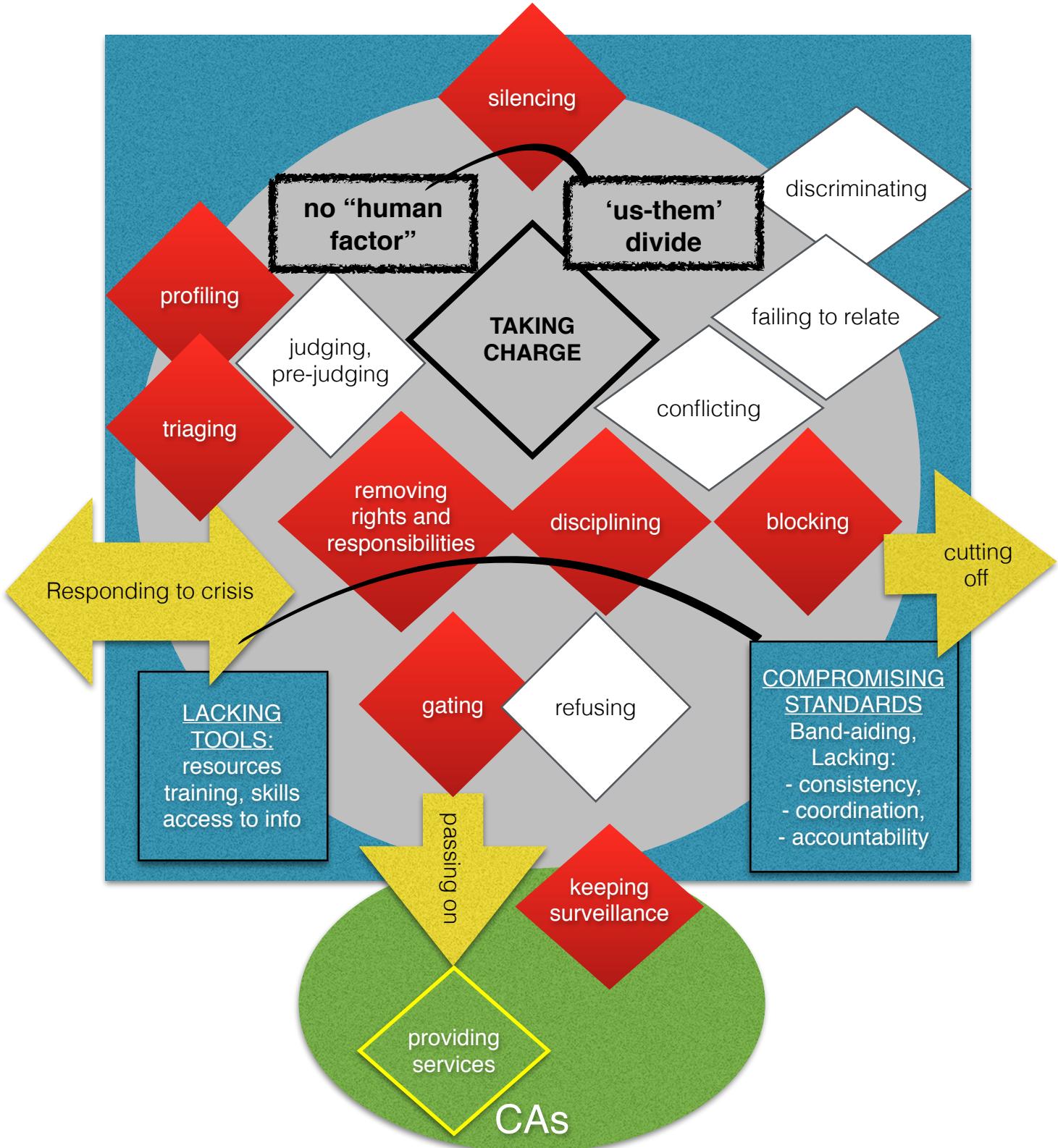
##### **[controlling]**

- increasing likelihood of a predetermined response from anyone who accesses the file

## Appendix M: Diagramming

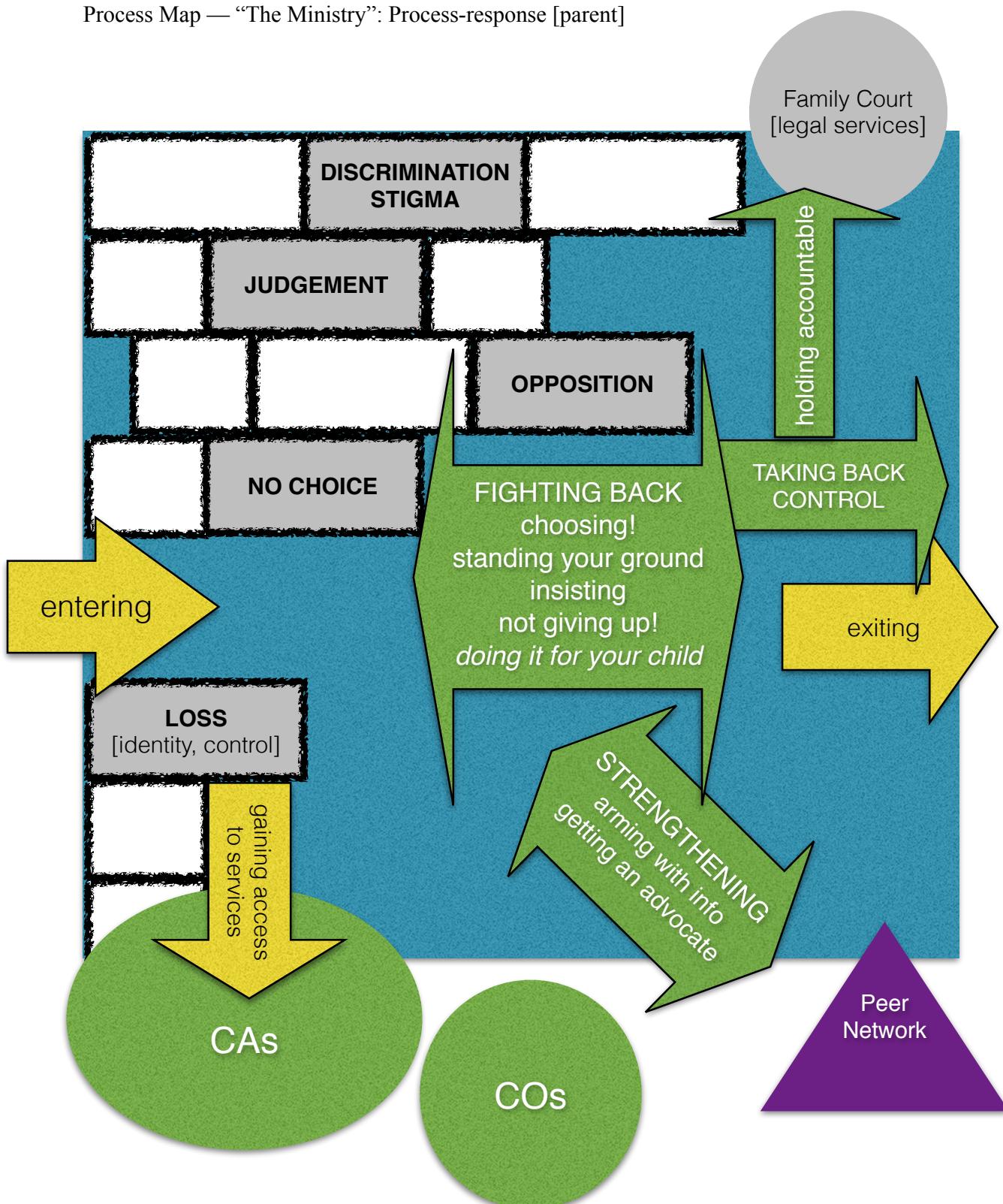
### Example 1

Context Map — “The Ministry”



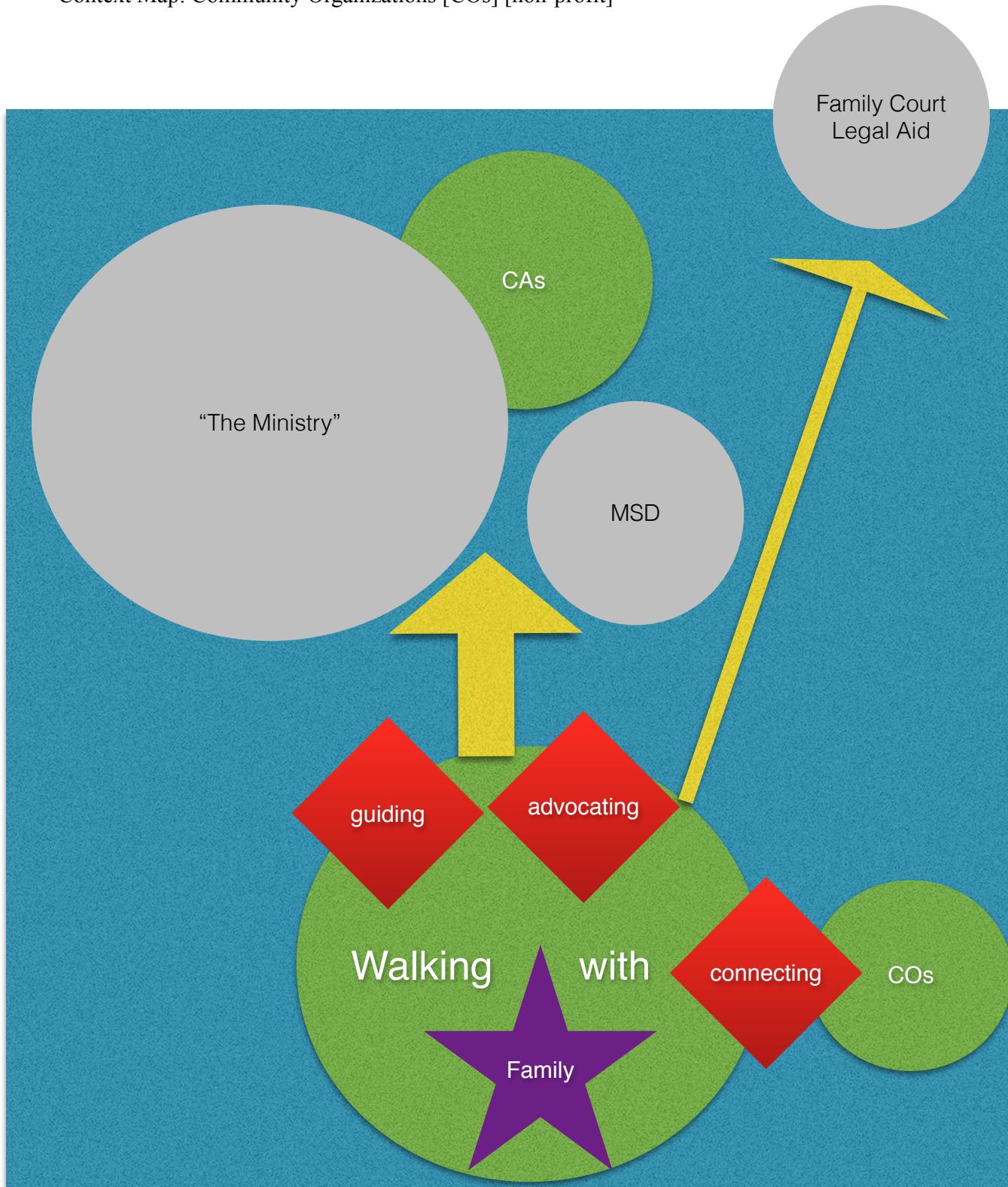
### Example 2

Process Map — “The Ministry”: Process-response [parent]



**Example 3**

Context Map: Community Organizations [COs] [non-profit]



## Appendix N: Interim Report

*Views and Experiences of Parents with Mental Illness of Parenting Services: Interim Report*

June, 2015

For questions or comments about this report, please contact Ginna Abramovitch at  
[ginna\\_abr@yahoo.ca](mailto:ginna_abr@yahoo.ca) or 778-558-5509

*I would like to extend my sincerest thanks to all the participants in this study for your generosity in giving your time and sharing your stories.*

### ***Introduction***

This study attempts to elicit the expertise of parents with mental illness on the process of engaging with parenting services.

Eight parents contributed to this report. Participants came from diverse cultural backgrounds and personal histories. All had extensive experience with parenting services.

Two parent discussion groups were completed November 2014 and February 2015. The groups were held at the [REDACTED] ( [REDACTED] ) [REDACTED] office and each was approximately 2.5 hours in length. Each group had three participants; a total of six parents took part in the groups. Additionally, there were three individual interviews in October and November of 2014; a total of two participants took part in the interviews. These were done at a location most convenient to the participants and lasted approximately 1.5 hours each.

The discussion groups were led by this researcher and supported by [REDACTED], [REDACTED], [REDACTED]. [REDACTED] is known to all the participants as a service provider and has acted in a supportive role throughout this study. Her help has been invaluable.

The opening questions for discussion groups and individual interviews were: *What types of parenting services have you come in contact with? What has been your experience with parenting services?* Followup questions were: *What has contributed to successful experiences? What has contributed to unsuccessful experiences?* These questions explored key elements of the parents' experiences with services, *from their perspective*.

The wrap up questions were: *What would you say to service providers? What would you say to parents who are looking for parenting services?* These questions elicited the parents' expert opinion on what is most important in (a) providing a successful service experience and in (b) managing the process of engaging with services.

The interim report summarizes participant's responses in the study up to this point. It is divided into three sections. The first section focuses on the process of engaging and the impact of this process on the parent. It also represents the parents' responses within this process. The second section identifies the supportive context and processes in more detail. The final section of the written report lists the parents' recommendations. Key processes of engaging with services, parent's responses, and the supportive context are mapped in three corresponding figures (A, B, C). These are available in the Appendix.

This report is intended for the participants' review. Feedback will be treated as data in the study.

*As you are reading this report and reviewing the graphs, please keep the following questions in mind: Does the information represent my experience? What stands out as most relevant? What is missing?*

*There is a brief questionnaire attached to the report for your comments; however, please comment in any way that suits you best. Please see the questionnaire for details.*

---

## ENGAGING WITH PARENTING SERVICES

The context of parenting services described in this report encompasses the communities of Vancouver, Burnaby and Richmond. Participants identified two main service domains: government and community. Primary government services — referred to by many participants as “the system”— were identified as the following:

- \* the Ministry of Children and Family Development (referred to as “The Ministry”)
- \* the Ministry of Social Development (MSD)
- \* BC Housing
- \* and Adult Mental Health Services (e.g. psychiatric services)

Individual schools (elementary and high school) and school-based programs as well as pro-bono legal services (e.g., Legal Aid) were also referred to as part of “the system”. Half of the participants also had contact with Family Court (FC); however, they tended to refer to “court” as a satellite of parenting services.

Community services composed mainly of Community Organizations (COs), e.g. non-profit agencies, peer support groups. Contracted Agencies of “The Ministry” (CAs) seem to straddle both domains. While CAs are predominantly non-profit community organizations, some of their services are only accessible through “the system” (namely, “The Ministry”).

### ***Encountering the “gap”***

*“they don’t make it easy”*  
—participant

Parents began their search for supports in the community. They described community supports as missing critical services and lacking a cohesive network. Some parents referred to this as the “Gap”.

Parents found that critical services (e.g., housing and income subsidy, psychiatric services, respite care) were not accessible in the community, i.e., only accessible through “the system”. Some parents also found that community services were a) open predominantly to low-income families; b) were only available during the day; or c) did not offer childcare. Hence, working parents found it especially difficult to access services.

Many parents spoke of information about services as “scattered”, outdated or missing. They described service databases as incomplete and difficult to navigate. Some parents found that information about services for people dealing with mental illness was not publicly accessible. Many parents talked about offering information to providers, rather than the reverse. Parents also found COs failing to reach out or to make their services visible.

The search for services, as one parent reflected, was “a full time job”. Parents identified the process of looking for services as exhausting reserves, exacerbating challenges, and increasing the sense of isolation. Families who fell through the Gap often ended up in crisis, which left them only one option: to enter “the system”.

### ***Experiencing “the system”***

Participants saw entering the system as “the only way” to get access to critical services:

- \* housing and income subsidy
- \* psychiatric and therapeutic services for the parent and child
- \* and respite care

However, the system did not make these services readily available or accessible.

#### *Entering*

The process of entering the system began with being triaged: *assessed for risks and problems* and *profiled* (as well as *labeled*) based on these assessments. Parents experienced the system as *gating* services: granting access based on extreme need.

Often the system placed the onus on the parents to prove they were really suffering. This process involved complicated steps and little guidance from providers; at times parents were misinformed or given contradictory information.

#### *Accessing*

Getting through this process did not guarantee services. At times the system failed to see need, despite clear indications. Some parents spoke of being denied income subsidy at critical times in their lives, e.g., after leaving an abusive partner or losing their jobs; or in the midst of recovering from a ‘mental break’. Others spoke of being denied access to safe family housing, even after being homeless. Several parents had been on the wait list with BC Housing for years and some were “still waiting”.

Parents also spoke of being offered services that didn’t come close to what they were requesting or needed. All parents on assistance, for example, had to also access food and clothing banks. The majority of parents identified the system failing to provide for their families’ basic needs and *band-aiding* problems as a direct result of being underfunded and lacking resources.

Many system services were offered through Contracted Agencies (CAs). Parents who were granted access to CA services received tangible supports, such as counselling for the child and parent. However, CA services were not without ‘strings attached’. CAs acted as informers to “The Ministry”: *monitoring* and reporting on parents’ progress. Majority felt that CAs offered excellent services, despite this handicap. However, most CA services became inaccessible once “The Ministry” file was closed.

#### *Enduring*

Many parents experienced providers engaging in system processes as *judging* (i.e., viewing with bias) and *depreciating* them. For example, parents spoke passionately against being reduced to problems or profiles and viewed this as profoundly stigmatizing. Parents also experienced system providers *removing their rights and responsibilities* (e.g., the right to make decisions for self and child), *disciplining them like children*, and *monitoring* them for any mistakes. Some parents linked these actions to providers’ working conditions: perpetually responding to crisis and lacking the resources to adequately respond to needs. Others questioned their training (i.e., as based on outdated perspectives and frameworks).

Parents' overall experience of the system was as *controlling and disempowering*. The most impactful process was *gating* access, and especially *denying or cutting off critical services*. Many parents felt that this was like pressing the restart button on the entire process, as it sent them back into the service Gap.

### ***Responding***

*"You can't give up!"*

—participants

Despite many parents feeling that they were unable to get ahead (or, for some, to return to a life before illness), all spoke of the importance of *not giving up* and of the gains that come with persevering.

Parents talked about *standing their ground*: *insisting* on competence; *demanding* choices and respect; and *always persisting*. Some parents spoke of the value of *being patient*. Others spoke of *acting from their values*. The values of family, connectedness, giving and helping featured most prominently in parents' stories. Some parents volunteered in their community; others offered help to neighbours and even strangers; all actively distributed information to peers and providers. These were the ways in which the parents resisted being controlled and disempowered.

Resisting led to *taking back control*. This involved '*arming*' with *information* (i.e., accessing any and all available sources) and *getting "backup"* (especially from a professional advocate). These actions empowered and changed the dynamic of the parent-provider relationship. Some parents felt that system providers were resistant to this change, as if they were threatened by the parent gaining strength and voice. Parents also talked about taking control through legal action. Those that did, felt that this was their only recourse to holding the system accountable.

First and foremost, resisting was *not giving up*: making ends meet on a daily basis, finding the right services, and fighting the pull of the illness. Not giving up meant having a purpose for the struggle, which all identified as *doing it for your child*. Many said, that if it wasn't for their children, they wouldn't keep doing this.

Not giving up meant *holding on to hope* for a better future for their children and family. Sharing the sense of hope was also important. One parent's words summed up the sentiments of many: "It's worth fighting for."

---

## SUPPORTING THE PARENTS

*“Don’t just do the talk - do the walk with us.”*  
—participant

### ***Supportive Context***

Participants identified providers and organizations that engaged in supportive processes. These were seen as extra-ordinary individuals.

Contracted agencies (CAs) and other community organizations (COs) featured prominently in the parents’ accounts of supports. CAs’ strength and weakness was their tie to “The Ministry”. While allowing CAs to provide critical services, “The Ministry” also limited their effectiveness. COs’ weakness was inability to offer the same level of services as the CAs. Their strength was in *advocating* for the parent. Peer support groups also played a strong role in providing information to parents.

Government (or “system”) services had differentiated roles but were seen as exclusively focused on *meeting needs*. All fell short of succeeding. “The Ministry’s” supportive role was solely in connecting parents to CA services. The role of legal services was in advocating for the parent in the context of Family Court (FC). Lack of accessibility of pro-bono legal services was seen as their main weakness. While all participants were unable to afford lawyer services, they were also ineligible for Legal Aid services due to exceeding the income cutoff.

Individual schools were regarded as offering strong supports for children; and some school staff were seen as *collaborating* with parents. One participant also spoke highly of a community church organization that offered tangible benefits to the families (e.g., high quality food and clothing banks) as well as emotional support (e.g., peer support groups). However, this appeared to be a singular experience.

### ***Supportive Processes***

The process of *supporting recovery*, especially *meeting needs* and *maintaining connections* to families, was viewed by all participants as invaluable to the well-being of the parent and family. Connections bridged the service “Gap” and were critical to building supportive communities.

The process of *strengthening: advocating* and *guiding* was closely linked with *supporting recovery* in the parents’ accounts. *Advocating* was a key support to parents in the system, allowing them to retain a level of control over an otherwise ‘runaway’ process. *Guiding* often took the form of *providing accurate information* and *connecting to services*. Some parents likened this to motivating and empowering.

*Collaborating* was closely linked with both strengthening and supporting recovery. Parents spoke of a few providers that *treated them with respect* and *valued their contributions*. Collaborating involved *setting mutual goals* and *working together* to achieve them. Negotiating roles was clearly an important process in working together. Parents appreciated providers who did not expect them to do the providers’ job (e.g., locating resources) and who did not interfere in the

parents' duties (e.g., making decisions for the child and family). Community providers (from CAs and COs) were most commonly viewed as partners.

*Working relationally* was another significant process. *Giving time* meant caring and having a genuine intention to help. *Empathizing*: relating, recognizing both suffering and strength, was also highly valued. Some parents spoke passionately about providers *acting from the heart*: showing compassion and kindness without expecting anything in return.

*Working ethically* had significant consequences for providers. The parents highlighted the difficulty some providers had with reconciling *doing what is ethically and morally right* with working within (or with) the system. Parents spoke of extraordinary providers who risked their professional integrity (and their jobs) by choosing to do what they felt was right over 'going by the book'.

Finally, parents talked about providers *doing due diligence: communicating, following up, searching for solutions*. These were seen as basic supportive processes, without which even the best intentions meant little.

It was clear from the parents' accounts that the supportive context is lacking an integrated, cohesive 'system'. Without this, exceptional individuals are like threads of a broken web, unable to catch the family when it is falling or to fully support it in getting back up.

## **TEARING DOWN WALLS - BUILDING BRIDGES**

Participants saw "the system" and the community as needing significant improvements. Participants were keenly aware of the impact of underfunding across service domains and it was clear that rectifying this would have to be the first step. Some parents spoke of revamping "the system": changing the way it operates and relates to community services.

Several questioned the system's monopoly on basic needs services. The majority felt strongly that *opening access* to services would *stop the cycle* of crises and facilitate recovery.

All parents spoke of quality of services as essential. Parents talked about providers acquiring better (and ongoing) training as well as taking more time to engage with the parent and family.

Many parents talked about the need to address systemic and personal bias against parents with mental illness. Some parents saw bias as arising from system processes (e.g., looking for problems, profiling) and the conditions that maintained them (e.g., lack of training, missing frameworks). Participants urged providers to show more understanding and kindness.

Parents also talked about the importance of *building relationships*. They encouraged providers to get to know *them*, not just their files (or profiles). Some suggested that becoming aware of the family dynamics (including relationships with extended family members) and culture was instrumental to offering relevant supports.

Strengthening community resources was viewed by participants as imperative to *building a supportive community*. This included building bridges across the “Gap”: increasing availability and accessibility of services.

Participants spoke of the need for improving access to accurate information, including increasing public access. Some parents identified services that they viewed as logical ‘information hubs’: hospitals, schools, and social work services. Many viewed improvement as an outcome of increased coordination within and between community and system services.

Finally, participants’ responses highlighted the need for family-centred services that would provide the full continuum of supports for the child and parent: basic needs services; legal services; psychiatric and counselling services; and family services, such as respite and child recreation.

Overall, participants stressed the need for the service context to increase its capacity to serve the parent. In the words of one participant: ***“If you’re not addressing the parents’ needs, there is no healthy child.”***

## Appendix: FIGURES A, B, C

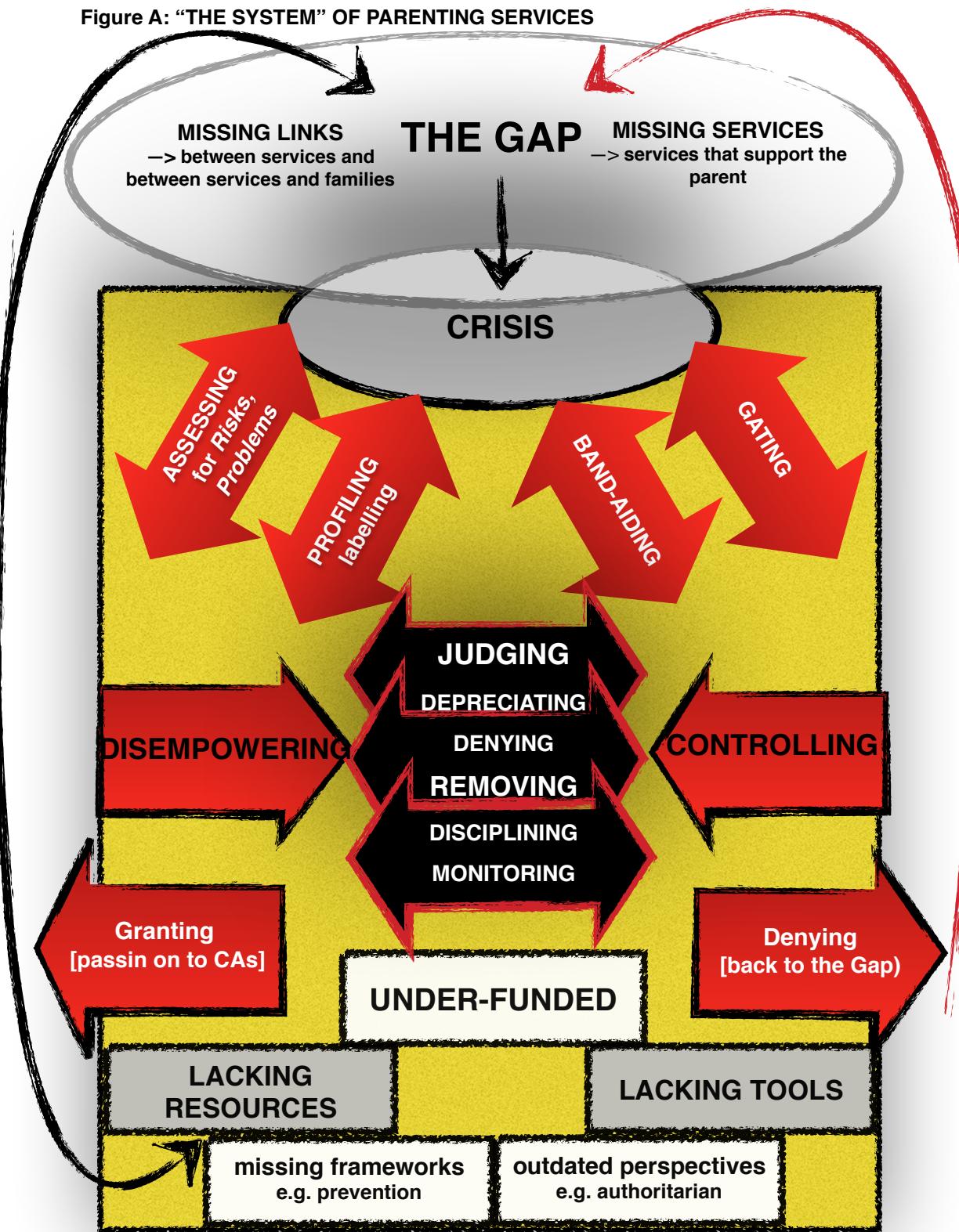
Figure A describes the conditions, processes and actions that the parents identified as definitive of “the system”. Conditions that were viewed as sustaining the system are represented as building blocks at the bottom of Figure A. All parents identified the primary sustaining condition of the system as under-funding. All system processes can be viewed as arising from these conditions. Red double arrows with white text at the top of Figure A are operational processes based in rules and regulations. These predominantly address crisis — another constant within the system. Processes represented by black double arrows are defined by their impact on the parents. Red side arrows with black writing are representative of the function of the system, from the parents’ perspectives; they can be viewed as outcomes of both operational and impact-processes. All processes can be viewed as mutually reinforcing.

Figure A also represents the “Gap” in community resources: missing services and links between services. The relationship between “the system” and the “Gap” can be viewed as mutually reinforcing, in the way of a vicious cycle. The “Gap” depletes parents of resources (e.g. personal strengths, family supports, finances), leaving them no choice but to enter “the system”, often in a state of crisis. Responding to crisis becomes the primary function of “the system”. Constantly responding to emergencies drains service resources and takes the focus away from prevention. This leaves a void in the community (i.e., creates the “Gap”). Weakening the community’s response ensures a steady flow of families in crisis entering “The System”. And so the cycle continues.

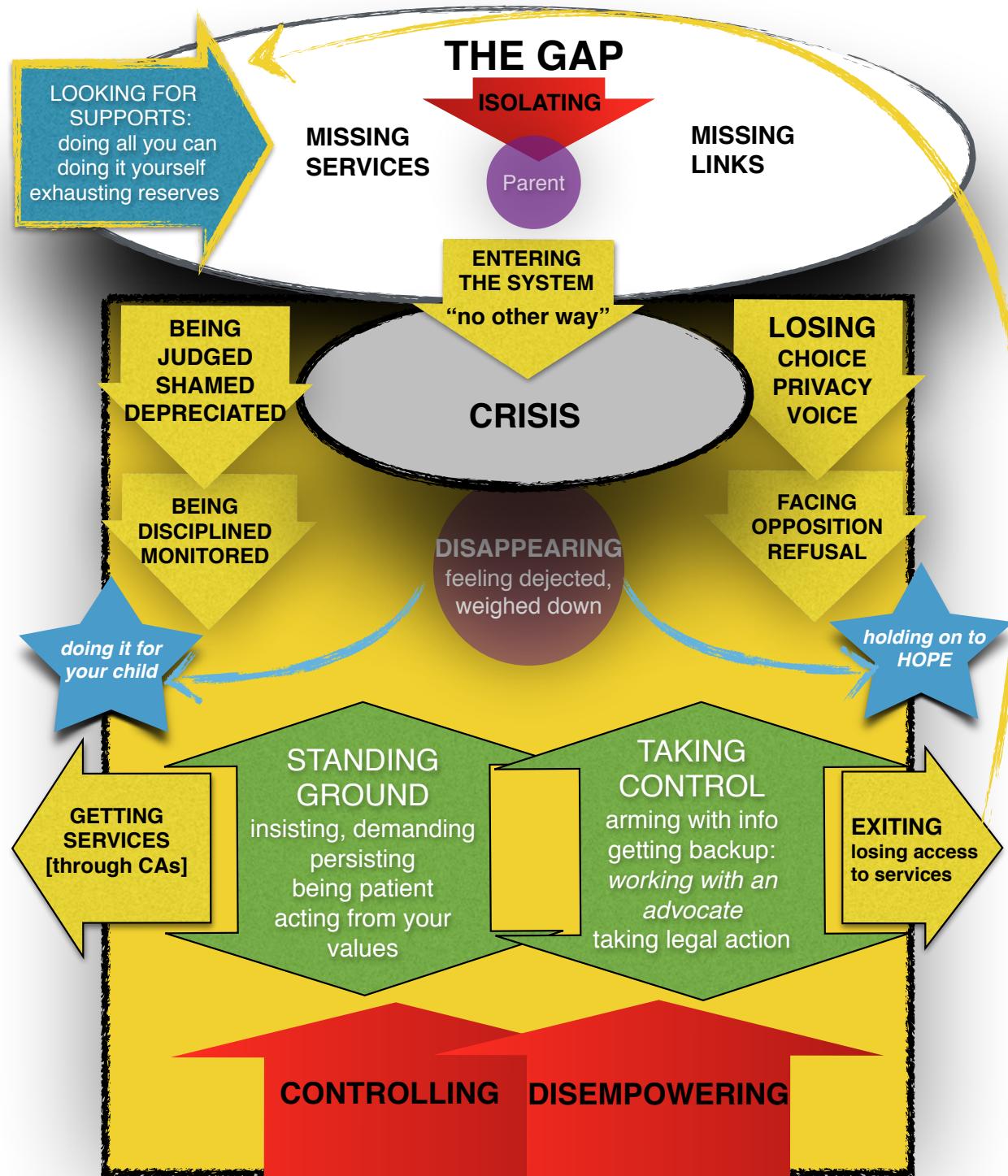
Figure B represents the parents’ process of engaging with parenting services, especially entering and being in the system. The parents’ movement through the system is represented by yellow arrows. Figure B focuses on the impact of the system on the parents, from their perspectives. It also represents the set of processes [red arrows at the bottom of the graph] that are definitive of the system’s function. The two green double arrows in the centre of the graph list the parents’ main responses to the system: *standing ground* and *taking control*. The two blue stars identify the parent’s sources of strength and motivation.

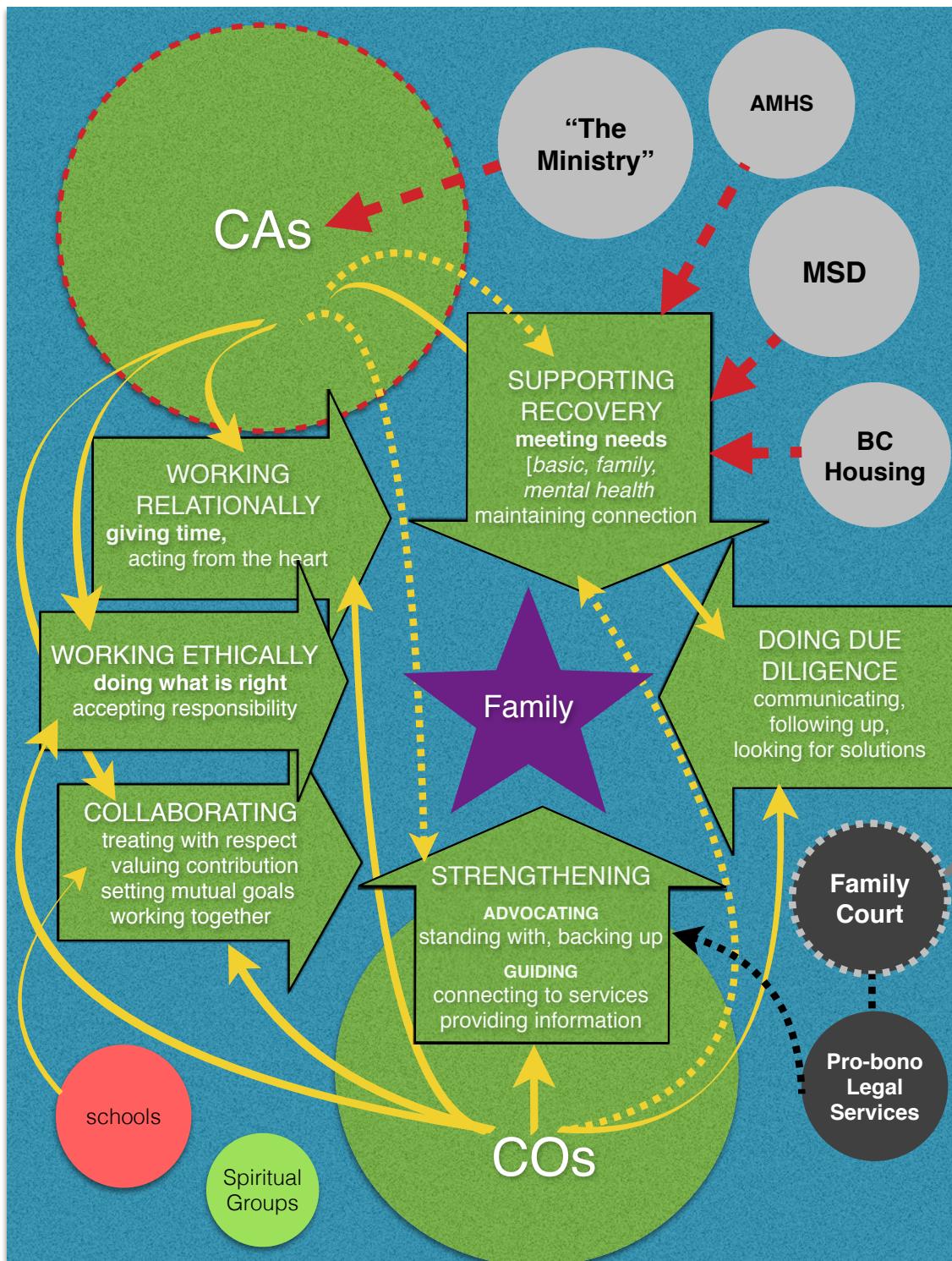
Figure C represents the context of parenting services and links service areas to supportive processes and actions [represented by the green arrows]. Prominence of a service area in the parents’ accounts of supports is represented by the size of the service spheres. Strong engagement in supportive processes is indicated by solid arrows. Weaker or partial engagement is represented by dotted arrows.

Figure A: "THE SYSTEM" OF PARENTING SERVICES



**Figure B: PARENTS' PROCESS AND RESPONSE**



**Figure C: SUPPORTIVE CONTEXT**

## Appendix O: Comment Survey

### COMMENT SURVEY: Review of Findings from the Interim Report

---

Please take a few minutes to fill out this survey. Your comments are very much appreciated! ***Please feel free to fill out as much or as little as you like.***

---

If you would like to respond by email, please send your answers to [ginna\\_abr@yahoo.ca](mailto:ginna_abr@yahoo.ca)

If you would like to discuss the report by phone, please contact me at 778-558-5509

---

#### How would you rate your overall agreement with the findings?

- Strongly agree       Agree       Disagree       Strongly disagree  
 I agree with some things and disagree with others       I am undecided
- 

#### What do you DISAGREE WITH?

#### What do you AGREE WITH?

#### What stood out for you as most RELEVANT (i.e. most important to you)?

---

**What was MISSING?**

---

**ADDITIONAL COMMENTS:**

*Please feel free to comment as little or as much as you like (here, in an email, or by phone)*

---

**PLEASE RETURN THIS FORM BY AUGUST 1, 2015**

If you would like to respond by email, please send your answers to [ginna\\_abr@yahoo.ca](mailto:ginna_abr@yahoo.ca)  
If you would like to discuss the report by phone, please contact me at 778-558-5509

---

**THANK YOU SO MUCH FOR YOUR TIME AND YOUR DEDICATION TO THIS TOPIC!  
YOUR COMMENTS ARE INVALUABLE TO THIS RESEARCH!**

## Appendix P: Final Report

***Experiences of parents with mental illness of parenting services:  
Directions forward.***

***Final Report.***

September, 2015

---

For correspondence related to this study, please contact Ginna Abramovitch  
at School of Child and Youth Care, University of Victoria  
[ginnaabr@uvic.ca](mailto:ginnaabr@uvic.ca)

## ACKNOWLEDGEMENTS

---

First, I would like to extend my sincerest thanks to all the study participants for their generosity and spirit. Their strength of character and dedication to their families and communities is truly inspiring. I hope that through this and future related efforts I am able to honour their contributions.

I would also like to thank the partnering community agency — without its support this project would not be possible. (The name of the agency is withheld from this report to protect the anonymity of research participants.) A special thanks goes to the agency representative whose professional commitment to the study participants ensured a safe and successful process for everyone.

Finally, I would like to acknowledge the support provided by the University of Victoria in completion of this MA thesis project. I would like to thank the faculty and students of the School of Child and Youth Care and, in particular, my thesis committee members, for their support and encouragement.

## Table of Contents

---

Acknowledgements -----	i
Summary -----	iii
The Study -----	iv
Section I: Engaging with parenting services -----	1
Falling through the “gap” -----	2
Figure 1: SERVICES PATHWAY -----	3
Experiencing “the system” -----	4
Getting through the gate -----	4
Being granted access -----	5
Enduring the process -----	6
Figure 2: “THE SYSTEM” -----	7
Seeing the ‘Big Picture’ -----	8
Responding: Not giving up -----	10
Figure 3: PARENT RESPONSE -----	11
Section II: Supporting the parents -----	13
Supportive processes -----	13
Figure 4: SUPPORTIVE CONTEXT -----	15
Section III: Tearing down walls — Building bridges -----	16
Conclusion -----	20

## SUMMARY

---

This report presents the findings of an exploratory research study on the experiences of parents with mental illness (MI) of parenting services, *from the parents' perspective*. The findings point to the direct impact of the parenting services context on the process and outcome of parental engagement with these services.

Parents described “the system” of government services as having a monopoly on essential services (e.g., housing/income subsidy, psychiatric services); as providing these services only in response to crisis; and as gating access to most community services (i.e., mandating the parent have an ‘open file’ in “the system”). From the parent’s perspective, restrictions on access to essential services *contributed to family crisis and breakdown and facilitated access of “the system” through emergency services*.

Entering “the system” meant enduring systemic ‘flaws’, including: discriminatory processes (e.g., profiling and triaging based solely on risks); poor coordination of services; inability to match response to needs; and failure to support recovery. Most system providers were viewed as engaging in harmful actions: belittling the parents, negating parental rights, and enforcing punitive measures for perceived mistakes. These actions and processes were experienced as *controlling and disempowering*.

Community services — government contracted agencies (CAs) and non-contracted organizations (COs) — were viewed as supportive (e.g., collaborating, guiding) and as providing tangible benefits to the parents and families (e.g., counselling, advocacy). However, the efficacy of CAs was perceived to be compromised by restricted access (i.e., access through “the system”) and contractual obligations (e.g., reporting on the family). COs had more flexibility in how they operated and offered open (unrestricted) access; however, they did not have the capacity to provide the same level of services as CAs or “the system”. The whole of community services were viewed as lacking coordination and therefore *failing to connect parents to services when they needed them*.

Deficits in the services context — within community and government services — were experienced as blocking recovery gains and locking the parent and family into a cycle of dependence on “the system”. Therefore, the services context was viewed as *perpetuating marginalization and stigmatization of parents with MI and their families*.

Participants made several ***key recommendations*** for necessary changes, including: lifting restrictions on access to essential and CA services; strengthening the capacity of community services to effectively respond to the needs of parents with MI and their families; expanding the public health perspective to encompass preventive services and treatment for parents and families affected by MI; targeting stigma against parents with MI in the general and the professional community; and actively *facilitating opportunities for parents' voices to be heard and parents' recommendations to be reflected in how parenting services are delivered and evaluated*.

## THE STUDY

---

Eight (8) parents with mental illness (MI) contributed to this study. Participants came from diverse cultural backgrounds and personal histories. All had extensive experience with parenting services — government and community. At the time of the study, participants were utilizing the services of a non-profit community agency serving families affected by mental illness.

The community agency partnered on the project, providing access to potential participants and physical space for research activities. It also provided compensation for transportation costs to participants of parent discussion groups. An agency representative supported the project in the following roles: initial recruiter; co-facilitator of discussion groups; and professional support to participants throughout their engagement with the study. She also assisted with transportation for some of the parents, which proved invaluable to securing their participation in the discussion groups.

The study utilized exploratory methodology, informed by Constructivist Grounded Theory, as presented by Kathy Charmaz (2006)<sup>1</sup>. The data collection was completed in two phases. Phase I composed of two (2) parent discussion groups (in November 2014 and February 2015). The groups were held at the partnering agency, in Vancouver, and each lasted approximately two and a half (2.5) hours. Each group had three (3) participants for a total of six (6). Participants were given the option of a one-on-one interview as an alternative to group participation. Two (2) participants chose this option, completing a total of three (3) individual interviews (in October and November 2014). Phase II composed of follow-up interviews with two (2) participants from Phase I. A total of three (3) interviews were completed in Phase II (in April and May 2015). All individual interviews and preliminary tasks (e.g., signing of consent forms) were done at locations chosen by the participants as most convenient (e.g., participant's home, community coffee shop, partnering agency). Each interview lasted approximately one and a half (1.5) hours.

Data collection began with the following questions:

*What types of parenting services have you come in contact with?*

*What has been your experience with parenting services?*

Followup questions were:

*What has contributed to successful experiences?*

*What has contributed to unsuccessful experiences?*

These questions explored key elements of the parents' experiences with services, from their perspective.

---

<sup>1</sup> Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative research*. Thousand Oaks, CA: Sage.

The wrap up questions were:

*What would you say to service providers?*

*What would you say to parents who are looking for parenting services?*

These questions elicited the parents' views on what is most important in (a) providing a successful service experience and in (b) managing the process of engaging with services.

An interim report on findings from Phase I was compiled in June 2015 and sent out to interested participants for review and comment. Six (6) participants were reached at that time; three (3) chose to offer comments on the report. Participants' comments guided the analysis of data, i.e., clarified direction of analysis and relevance of developing ideas.

Phase II interviews composed of questions that explored in more detail some of the key themes identified during analysis of data from Phase I. Examples of these themes:

- Impact of "the system" processes on the parent and family
- Perceptions of the influence of service providers' working environment (e.g., duties, mandates) on approach to service delivery
- The 'big picture' of services for parents with mental illness
- Directions forward

These interviews focused on developing the emerging interpretation of the processes and contexts of parietal engagement with parenting services as well as on parents' recommendations for how to accomplish necessary changes.

The final report presents the findings of the study in three sections. Section I: *Engaging with Parenting Services*, focuses on the parents' process of accessing and utilizing parenting services, highlighting the impact of this process on the parents with MI and their families. Section I also represents the parents' responses to the parenting services context, especially to "the system" of government services. Section I contains three (3) Figures: Figure 1: Services Pathway; Figure 2: "The System"; and Figure 3: Parents Response. These figures are intended to aid the presentation of findings and correspond to sections of the report.

Section II: *Supporting Parents*, illustrates the supportive context and processes in more detail. Section II contains Figure 4: Supportive Context.

Section III: *Tearing Down Walls - Building Bridges*, lists the parents' recommendations for a responsive and responsible services community that is able to engage and support parents with MI and their families. These recommendations are considered instrumental to fulfilling the intent of this study: to facilitate needed changes within the parenting services context through the engagement of parents with MI in service planning and evaluations.

## SECTION I: ENGAGING WITH PARENTING SERVICES

---

The context of parenting services described in this report encompasses Vancouver, Burnaby and Richmond. Participants identified two main service domains: government and community. These domains were distinguished by perceived authority over the family, demands on the parent, and approach to service delivery.

Participants identified the following primary government services — referred to by the majority as “the system”:

- Ministry of Children and Family Development (referred to as “The Ministry”)
- Ministry of Social Development and Social Innovation (MSD)
- BC Housing
- Adult Mental Health Services (primarily psychiatric services)

Individual schools (elementary and high school) and school-based programs as well as pro-bono legal services (i.e., Legal Aid) were also referred to as part of “the system,” though appeared less frequently in the parents’ accounts. Additionally, half of the participants had contact with Family Court (FC); however, they tended to refer to “court” as a satellite of parenting services.

Government services had the most power to affect the parent and family, especially as they held the monopoly on essential aid (e.g., income and housing subsidy). These services placed the most demands on the parent and enforced the expectation of compliance, frequently through what the parents perceived to be punitive measures.

Community services consisted of government contracted agencies (CAs) and non government contracted organizations (COs). Community services were perceived as having the most supportive (e.g., collaborative) approach to service delivery. However, they held less power than government agencies to affect change for the parent and family.

COs were non-profit agencies that provided the most low-barrier access to services. However, they appeared to be the least able to provide tangible benefits to the parent and family and were the least frequently mentioned.

Contracted agencies (CAs) — mainly contracted by “The Ministry” — muddled the domain boundaries. While CAs were non-profit community organizations, majority of their services were inaccessible through the community, i.e., only accessible through “the system”. CAs were also frequently viewed as government representatives — a role that was reinforced by contractual restrictions on access and obligations to monitor the parent and family on behalf of the government agency. On the other hand, the CAs’ approach to service delivery aligned them with other community-based services (COs).

## FALLING THROUGH THE “GAP”

“They don’t make it easy”  
— participant

Parents who began their search for services in the community encountered a services “gap”: missing services and missing links (a) between services and (b) between parents and services. Essential services (e.g., housing and income subsidy, psychiatric services) were strictly the domain of “the system”. While many other potentially beneficial services (e.g., counselling for the parent and family) — despite being community-based — were only accessible to parents who were ‘in’ “the system” (i.e., had an open file with a government agency).

Community-based parenting services that did not require that the parent was ‘attached’ to a government agency also restricted access. Some based eligibility on the parent’s income, opening access only to low-income families. Others limited access based on the parents’ cultural or ethnic affiliation. Some services were inaccessible due to limiting operations to day-time hours and/or failing to eliminate barriers (e.g., did not provide childcare or assistance with transportation).

Parents also encountered outdated, “scattered,” and missing information about parenting or mental health services. Parents spoke of having to do extensive research and source out information from all available avenues, including from parenting groups and peer networks. They described service databases as incomplete and difficult to navigate. They identified service providers (across domains) as poorly informed and often unable to offer appropriate referrals. Many parents talked about offering information to providers, rather than the reverse. Additionally, parents found community organizations (COs and CAs) failing to reach out. This appeared to be especially true of agencies that geared their services towards persons and parents with MI.

Some parents were able to commit to the “full time job” of actively seeking services. Others spoke of having no such opportunity. This was especially true of working parents; parents who had extensive fami-

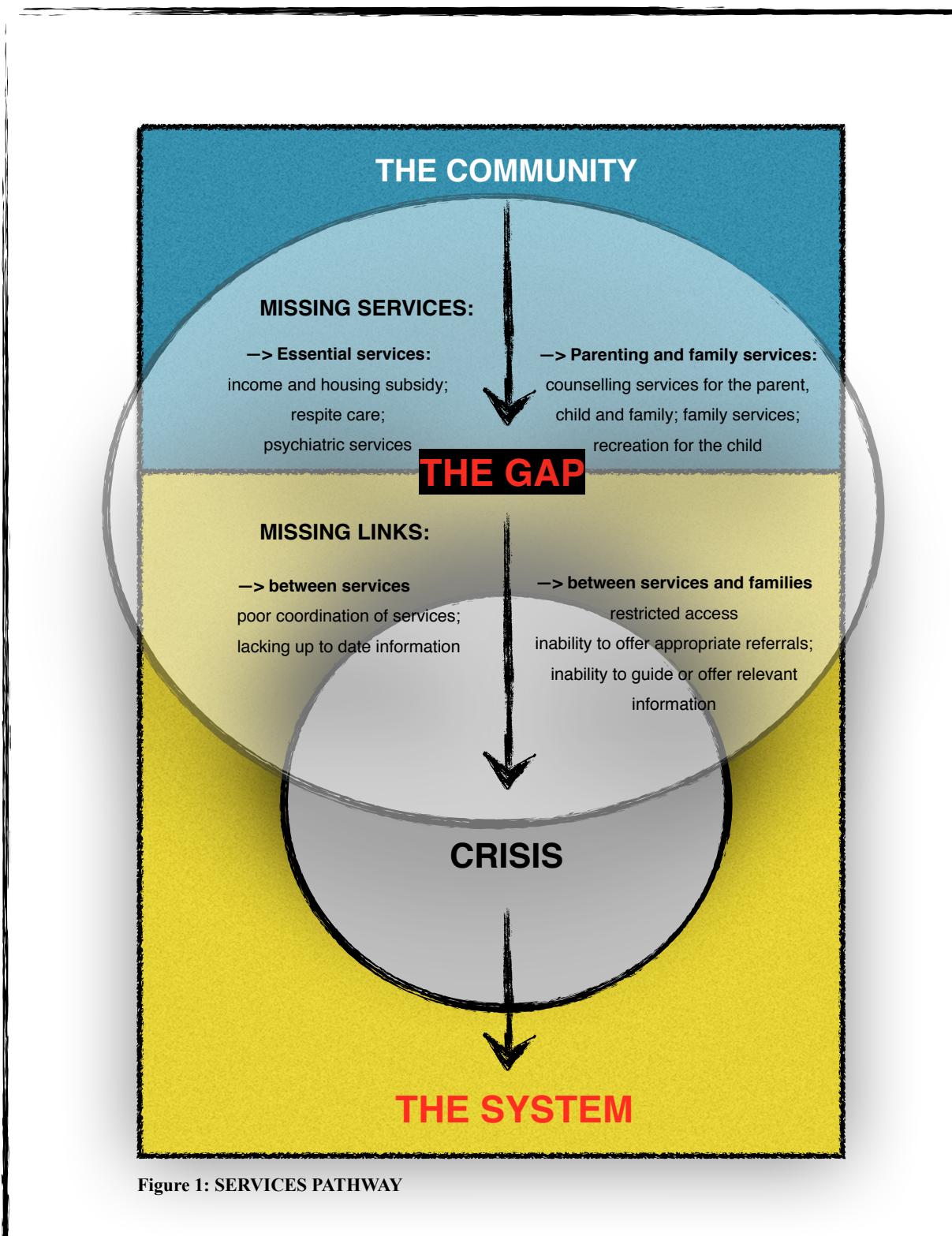
ly obligations; and those who had few (or no) family/personal supports. While the apparent lack of an information ‘system’ and relative invisibility of mental health services made accessing community services a frustrating experience for all parents, these deficits ensured that parents who had barriers to actively seeking services were disconnected from community supports.

Many parents identified a profound sense of isolation that accompanied the process of searching for services in the community. Parents identified feeling unable to meet per-

### BARRIERS TO COMMUNITY SERVICES:

- Lack of availability of essential parent and family supports
- Inaccessibility and invisibility of parenting and mental health services
- Lack of coordination of and public access to service information

sonal, family, and societal expectations of 'good parents'. Some parents also questioned whether asking for help meant that they were failing as parents.



*Falling through the services “gap”* was an overwhelming experience for the parents and families. Placing barriers to access or failing to remove existing barriers exhausted already depleted personal reserves and exacerbated often significant challenges (e.g., divorce, losing a job or housing, recovering from illness or injury). This often resulted in crisis for the parent and family, increasing the risk of a ‘mental break’ or relapse of symptoms of MI for the parent. Hence, *falling through the “gap”* often necessitated contact with emergency services. Typically, this path led directly into “the system” (Figure 1: Services Pathway).

## **EXPERIENCING “THE SYSTEM”**

“No one asks for this”  
— participant

Entering the system was “the only way” to get access to the following services:

- housing and income subsidy
- psychiatric and therapeutic services for the parent and child
- and respite care

It was also the only way to gain access to the majority of services provided by contracted agencies (CAs), such as counselling for the parent and family, parent support groups, and certain recreational opportunities for the child. The system’s monopoly on essential services and the barriers to services in the community drew a clear services pathway that led directly to the system (Figure 1).

Irrespective of participants’ prior experience with the system, all were aware of the potentially devastating impact of entering the system on the family (e.g., loss of child custody) and saw this as their “last resort”. It was clear from all accounts that the parents had done everything in their power to avoid this path. Ironically, attempting to avoid contact with the system led parents quicker to it, as they sacrificed their health and wellness in attempts to surmount the challenges of providing for their children and family without adequate supports.

### **>>>GETTING THROUGH THE GATE**

Whether the parents entered the system through emergency services (i.e., were in crisis) or they requested access (i.e., were acting preemptively), the system initiated what many parents viewed as a crisis response: *profiling* based on risks and problems, and *triaging* based on indicators of ‘extreme need’.

Parents experienced the system as *gating* services: granting or denying access based on the criteria of ‘extreme need’. Parents’ accounts demonstrated that access was dependent on the

“If I need help - I NEED help”  
— participant

system provider's interpretation of whether the parent 'fit' the typical system profile of the "extreme case". If the parent's presentation did not 'fit,' access was refused or restricted. If the parent was returning to the system, access was dependent on the interpretations contained within the old file.

Typically, the system placed the onus on the parents to prove that they were really suffering. Access to services was further dependent on the parents' ability to negotiate the administrative process of *proving need*. This process involved complicated steps (e.g., multiple forms, appointments with specialists). Parents found that most system providers did not offer guidance and typically passed the parent on to another provider. Parents described being bounced like a "ping pong" from source to source and at times being given contradictory or erroneous information. Few community providers aided the parents in this process; those that did, typically did not have government contracts.

Having to 'jump' through administrative 'hoops' was exhausting and discouraging. Parents found that there was little regard in this process for the effects of mental or physical illness (e.g., low energy, pain, distress) or for the emotional impact on the parent of entering the system (e.g., having to depend on system 'handouts'). Parents reported that inability to meet process demands was viewed by system providers as evidence that the parent and family had alternative resources or as non-compliance — both interpretations jeopardized the parents' access to services.

>>>**BEING GRANTED ACCESS**

"It always comes from a place of pain"  
— participant

*Getting through the gate* via emergency services meant an influx of services that was described as overwhelming. This process assured that the parent was contacted by "The Ministry" (MCFD). It also typically facilitated parents' access to psychiatric and social work supports. Parents described the sudden appearance of services as starkly contrasting their silence in the community, prior to the parent being in crisis.

*Getting through the gate* did not guarantee services, however. At times the system failed to provide, despite clear indications of need. Parents spoke of being denied income subsidy at critical times in their lives, e.g., after leaving an abusive partner or losing the only means of income; as well as being denied access to safe family housing, despite the family being homeless. Parents had been on the wait list with BC Housing for years prior to being granted access and a few were "still waiting".

Parents also spoke of being offered services that didn't come close to what they were requesting or needed. For example, all parents on income assistance had to regularly access food and clothing banks. Parents identified the system as failing to adequately meet their families' basic needs and as providing inadequate solutions to problems, i.e., *band-aiding* rather than addressing problems.

*Being granted access* also frequently meant being *passed on* to a different department and/or another provider. It was not unusual for parents' files to change hands several times during their time 'in' the system. Changing providers meant having to start over: having to yet again prove need, comply with more administrative demands, and attempt to build a new provider-parent relationship. *Changing hands* was experienced as difficult and discouraging, especially as this sometimes compromised access to services.

Majority of system services were offered through contracted agencies (CAs). *Being granted access* meant receiving tangible benefits that supported the parents' recovery and strengthened the family. However, CA services came with 'strings attached'. CAs acted as informers to their government contractor: *monitoring* and reporting on parents' progress.

All parents, however, spoke of CAs offering excellent services, despite this handicap. CAs' main weakness was identified as restricting access, especially cutting off access once the parent was no longer 'in' the system. While some CAs attempted to negotiate an alternative service arrangement with the parent and family (e.g., charging for services on a sliding scale), most became inaccessible to the parent and family 'outside' the system.

#### **>>>ENDURING THE PROCESS**

Parents experienced the system and majority of system providers as *controlling and disempowering*. For all parents accessing the system meant *losing choice, privacy, and voice*. Parents endured system providers *negating (and often removing) their rights and responsibilities* (e.g., the right to make decisions for self and child) and *opposing them* in their attempts to retain or regain the ability to make decisions for themselves and their children. Parents' accounts identified system providers *disciplining* them like children and constantly looking for perceived mistakes. All parents identified the system as enforcing punitive measures for what it regarded as non-compliance with demands and expectations. Parents' accounts highlighted these as responses especially typical of The Ministry.

Majority of parents viewed system processes as profoundly *stigmatizing*. Many also faced what they considered to be discrimination from system providers against parents with MI and parents coming in contact with system services (especially with services of The Ministry). Parents experienced system providers as *judging* and *belittling* them, e.g., dismissing abilities and strengths; ignoring parents' assessments of their needs and requests for services; and typically viewing them as 'the problem'. Invariably, these actions and processes damaged the parents' self-worth, often compounding the challenges of MI and hindering recovery.

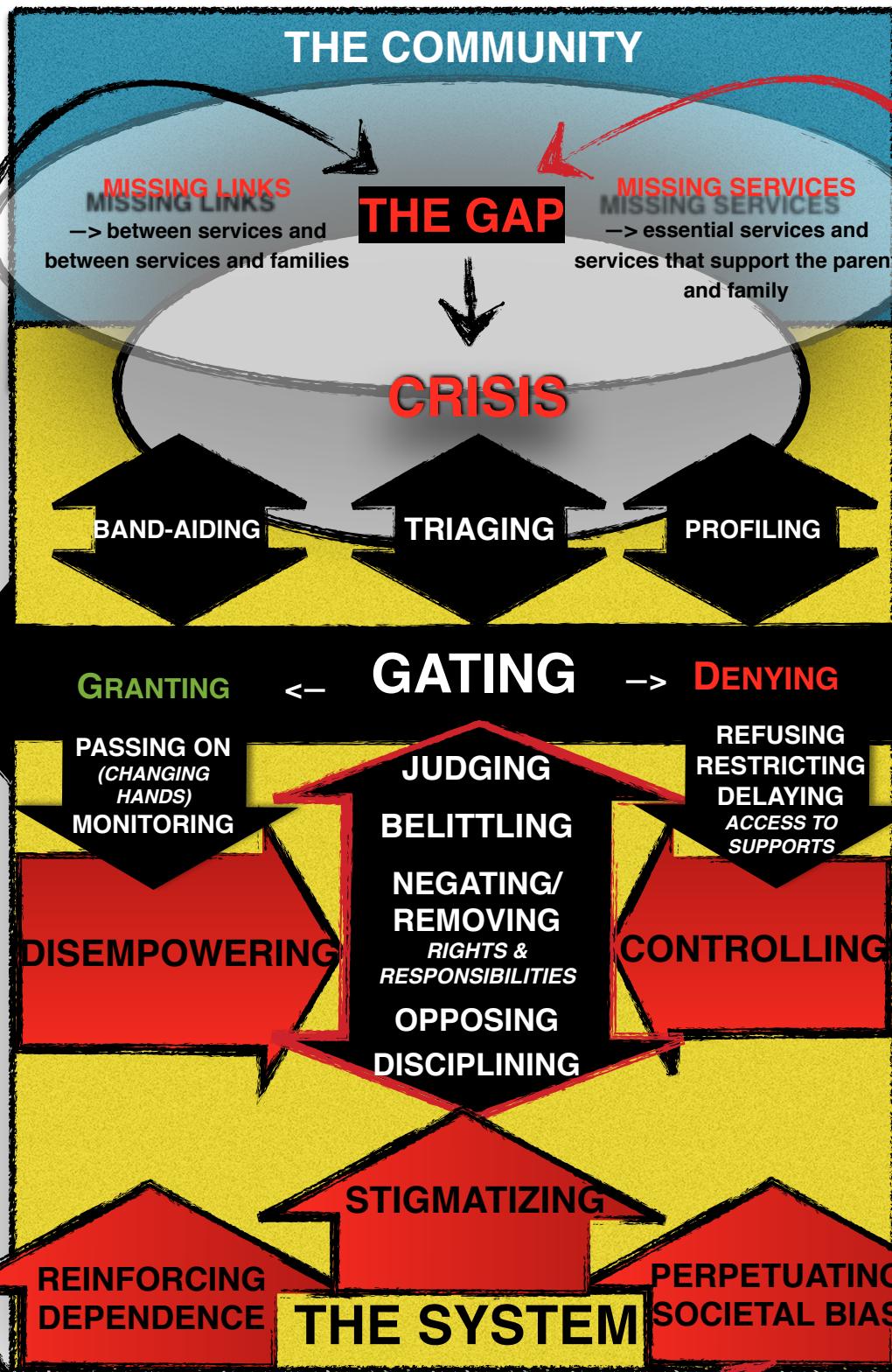


Figure 2: "THE SYSTEM"

## **SEEING THE ‘BIG PICTURE’**

There were undeniable benefits from entering “the system,” such as gaining access to essential aid and services that could offer tangible benefits to the parent with MI and family. However, there were significant drawbacks that all but outweighed these benefits.

*Gating* access to services — especially *restricting, denying, or cutting off access to essential services* once the parent was ‘out’ of the system — had a pronounced impact on the parent and family as well as on the services’ ability to provide meaningful support. *Gating* access increased the risk of a mental illness ‘break’ or family crisis and encouraged entering the system through emergency services. Crisis compromised the parents’ ability to utilize services and delayed their recovery. Consequently, some parents saw the system’s restrictions on access as weakening the ability of services to produce lasting benefits and as contributing to parents being “caught” in the system’s ‘revolving door’. Many questioned the logic of a social system that reinforced dependence and one parent labeled such a system as “non-sustainable”.

Parents’ accounts underlined the system’s missing focus on prevention and supporting recovery. This was evident in the lack of availability and accessibility of certain recovery supports, such as safe affordable family housing and continued access to CA services. Many parents spoke of the difficulty of getting ahead of the next challenge and of moving forward, towards a desired future.

Most parents made the direct link between the system’s failure to meet needs and the ‘common knowledge’ of the system being underfunded and constantly cutting services. However, one parent questioned whether the system was marketing an image of being ‘underfunded’ as a public excuse for negligence. Counter to this image, some parents found a relative wealth of services once they were ‘in’ the system. However, availability did not seem to translate into ability to respond to needs. These experiences prompted some parents to question how system services were being managed.

A few parents criticized what they saw as the lack of accountability of the system to the public. Many parents felt that they had no recourse for the wrongful actions they experienced. One parent identified a lack of transparent, impartial, easily accessible complaints process. This further reinforced the parents’ perception of the system as working for itself, rather than for the best interests of the parent and family.

Parents also described system providers’ apparent lack of awareness of available resources (including ‘next door’ services) and consequent inability to offer information and referrals. This mirrored the parents’ experiences in the community. Some parents identified this as the result of poor coordination of system services, i.e., a lack of a cohesive, integrated services continuum.

Some parents saw the neglected focus on prevention and service delivery as a direct consequence of the system perpetually responding to crisis. Parents questioned system providers' training as targeted towards crisis-response and lacking in other processes and practices (e.g., mental health assessment and support). Others implicated system providers' working conditions — crisis-driven and demanding — in providers' inability to facilitate a pre-emptive response.

Some parents questioned whether *triaging* had replaced comprehensive assessment. Parents talked about providers doing 'quick and dirty' assessments, as opposed to taking the time to listen and identify needs. All parents saw the system responding only to risks and problems. This prompted some parents to question assessment practices as biased or based on outdated perspectives and practice frameworks.

For all parents with MI, the experience of the system was punctuated by enduring stigma and what many saw as systemic discrimination against parents with MI and parents who must rely on government services. Parents identified system processes as both directly *stigmatizing* and as encouraging providers' bias, e.g., viewing the parent as a 'file' to be managed and passed on.

Many parents rebuked the system and system providers for *perpetuating societal bias* and discrimination. The parents' lived experiences reinforced their perception of the system as *misdirecting the public*: drawing attention away from the numerous problems, deeply ingrained within system operations by perpetuating the view of the parent as 'the problem'. A few participants directly implicated the system in perpetuating societal bias as a means of continuing operations without being held accountable to the obvious gaps between the system's mandates and outcomes.

*"That's the kind of awareness that's really out there. 'Oh well, it's those people. They're, they're always in the system.' So it's easy to brush off. People don't now stop and think, well, why are these people always in there?"*

— participant

The power of government agencies and their representatives (including CAs) to irreversibly affect the lives of parents and families was highlighted in all parents' accounts of their experiences with parenting services. For many parents the system was a mechanism of control and marginalization: a "gear in the larger machine," perpetuating the classist divide and oppression of the poor, the ill, and the disabled.

## **RESPONDING: NOT GIVING UP**

For many parents the reality of being part of the process of accessing system services meant an exacerbation of challenges related to dealing with MI. It meant being constantly reminded of the loss of certain abilities or of the self prior to illness. Many parents continued to grieve this loss, even after having made significant recovery gains. Those who experienced the (temporary) removal of parenting rights and separation from their children were profoundly shaken by these events. The trauma of this experience was evident in their accounts — even years after — as was the fear of re-experiencing such loss.

Many parents spoke of feeling stuck: locked into a degenerative cycle by illness, but especially by the lack of resources to maintain recovery gains. Some identified being unable to provide for their families as a personal failure and being dependent on others as demoralizing. Some spoke of feeling like ‘a burden’ on friends and family and of contemplating ending the suffering by suicide.

This was the emotional reality for most of the parents dealing with MI — on top of the struggles of parenting and, for many, poverty, single parenthood, and multiple other stressors. Incredibly, in the face of these challenges, all parents spoke of the importance of *not giving up* and of the gains that come with persevering. In the context of the system that reduced people to ‘files’, invalidated rights, punished, controlled, and systematically stigmatized and disempowered, *not giving up* took every ounce of strength and will.

“You can’t give up!”  
— participants

*Not giving up* meant making ends meet on a daily basis and fighting the pull of the illness into despondency and isolation. Many did this by helping others: volunteering in their community; helping neighbours and even strangers.

Parents talked about *standing their ground: demanding choices and respect*. For some this meant insisting that system providers acknowledge their competence and strengths. For others this meant persistently repeating requests and restating needs. Many felt that these actions were necessary to gain access to system services.

Some parents were able to muster the strength and resources to attempt *taking back control: ‘arming’ with information* (by accessing any and all available sources) and *getting “backup”* from professional advocates. Parents who worked with advocates (exclusively from COs) felt that this always changed the dynamic of the parent-provider relationship. They saw system providers as being opposed to this change, as if they were threatened by the parent gaining strength and voice. Parents also talked about taking control through legal action. Those that did, felt that this was their only recourse to a fair resolution to disagreements with system providers, especially regarding the care of their children.

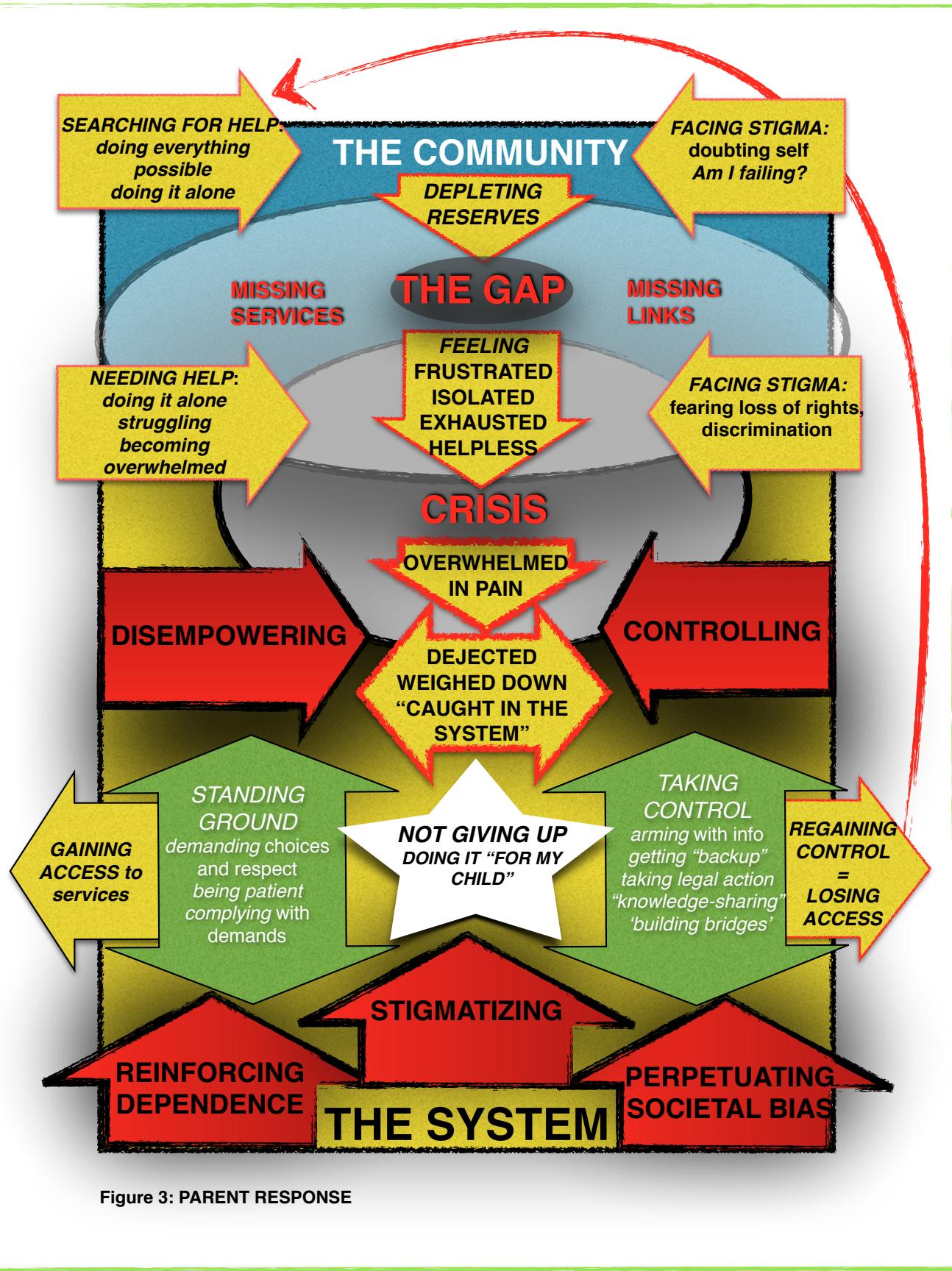


Figure 3: PARENT RESPONSE

Not all parents were fortunate enough to acquire the resources to directly challenge the system. Some felt that active resistance or disagreement was interpreted as non-compliance by system providers and could compromise their chances of regaining parenting rights and/or accessing services. Consequently, parents spoke of the importance of showing cooperation and ‘doing what they ask’. For these parents, *standing ground* meant *being patient* and *complying* with demands.

All parents actively distributed information to peers and providers. Through this “*knowledge-sharing*” parents were helping peers to respond to the system, to be better prepared to take back control, if the opportunity arose. In these ways parents were also contributing to a supportive community, *‘building bridges’* across the small ‘islands’ of isolated families struggling to keep afloat.

All parents identified their motivation for *not giving up* as *doing it “for my child”*. Many said, that if it wasn’t for their children, they wouldn’t keep doing this. Parents clearly foresaw the impact of ‘giving up’ on their children’s future and did everything in their power to persevere.

*Not giving up* also meant *holding on to hope* for a better future for their children and family. Sharing that sense of hope was just as important. One parent summed up the sentiments of others: “It’s worth fighting for.”

“It’s worth fighting for”  
— participant

## SECTION II: SUPPORTING THE PARENTS

---

Participants identified providers and organizations that engaged in supportive processes. These were seen as extra-ordinary individuals.

Contracted agencies (CAs) and other community organizations (COs) featured prominently in the parents' accounts of supports. CAs' strength and weakness was their tie to the system. While allowing CAs to provide critical services, the system also placed them in a conflict of interest — by mandating that they both support and inform on the parent and family. Some parents viewed system contracts as limiting CAs effectiveness, including making it difficult for CAs to advocate for the parents and families in the context of system service. Conversely, COs' strength was in *advocating* for the parents. Their weakness was the inability to offer the same level of services as the CAs. Peer support groups and networks also played a strong role in providing information to parents and in connecting parents to a supportive community.

"Don't just do the talk, do the walk with us"

— participant

Government (or "system") services had differentiated supportive roles (e.g., BC Housing only provided housing assistance). All were seen as exclusively focused on *meeting basic needs* of the family, but (at best) only partially fulfilling their respective roles. Parents identified "The Ministry's" sole supportive role as connecting parents to CA services.

The role of legal services was in *advocating* for the parent in the context of Family Court (FC). Lack of accessibility of pro-bono legal services was seen as their main weakness. While all participants (irrespective of whether they were working) were unable to afford lawyer services, most were categorized as ineligible for Legal Aid due to exceeding the income cutoff (i.e., making too much to be granted access).

Individual schools were regarded as offering strong supports for children; and some school staff were seen as *collaborating* with parents. One participant also spoke highly of a community church organization that offered practical supports to the families (e.g., a high quality food and clothing bank) as well as emotional support (e.g., peer support groups). However, this appeared to be a singular experience.

### >>>**SUPPORTIVE PROCESSES**

Exceptional individuals and services engaged in the processes of *supporting recovery, strengthening, collaborating, working relationally and ethically, and doing due diligence*. These individuals and processes were highly valued by all parents.

The process of *supporting recovery*, especially *meeting basic needs* and *maintaining connections* to families, was viewed by all participants as invaluable to the well-being of the parent and family. Connections bridged the service gaps and were critical to building and maintaining supportive communities.

The process of *strengthening: advocating* and *guiding* was closely linked with *supporting recovery* in the parents' accounts. *Advocating* was a key support to parents in the system, allowing them to retain a level of control over an otherwise 'runaway' process. *Guiding* often took the form of *providing accurate information* and *connecting to services*. Some parents likened this to the processes of motivating and empowering.

*Collaborating* was connected with both strengthening and supporting recovery. Parents spoke of a few providers that *treated them with respect* and *valued their contributions*. Collaborating involved *setting mutual goals* and *working together* to achieve them. Negotiating roles was clearly an important process in working together. Parents appreciated providers who did not expect them to do the providers' job (e.g., locating resources) and who did not interfere in the parents' duties (e.g., making decisions for the child and family). Community providers (from CAs and COs) were most commonly viewed as partners.

*Working relationally* was another significant process. *Giving time* meant caring and having a genuine intention to help. *Empathizing*: relating, recognizing both suffering and strength, was also highly valued. Some parents spoke passionately about providers *acting from the heart*: showing compassion and kindness without expecting anything in return.

*Working ethically* had significant consequences for providers. Parents commented on what they perceived to be especially challenging for some providers: reconciling *doing what is morally right* with working within (or with) the system. Parents spoke of extraordinary providers who risked their professional integrity (and their jobs) by choosing to do what they felt was right over 'going by the book'.

Finally, parents talked about providers *doing due diligence*: *communicating*, *following up*, *searching for solutions*. These were seen as basic supportive processes, without which even the best intentions meant little.

Overall, the parents' accounts identified a services context that was lacking an integrated, cohesive 'system' of supports. Without this, exceptional individuals were like threads of a broken web, unable to catch the family when it was falling or to fully support it in getting back up.

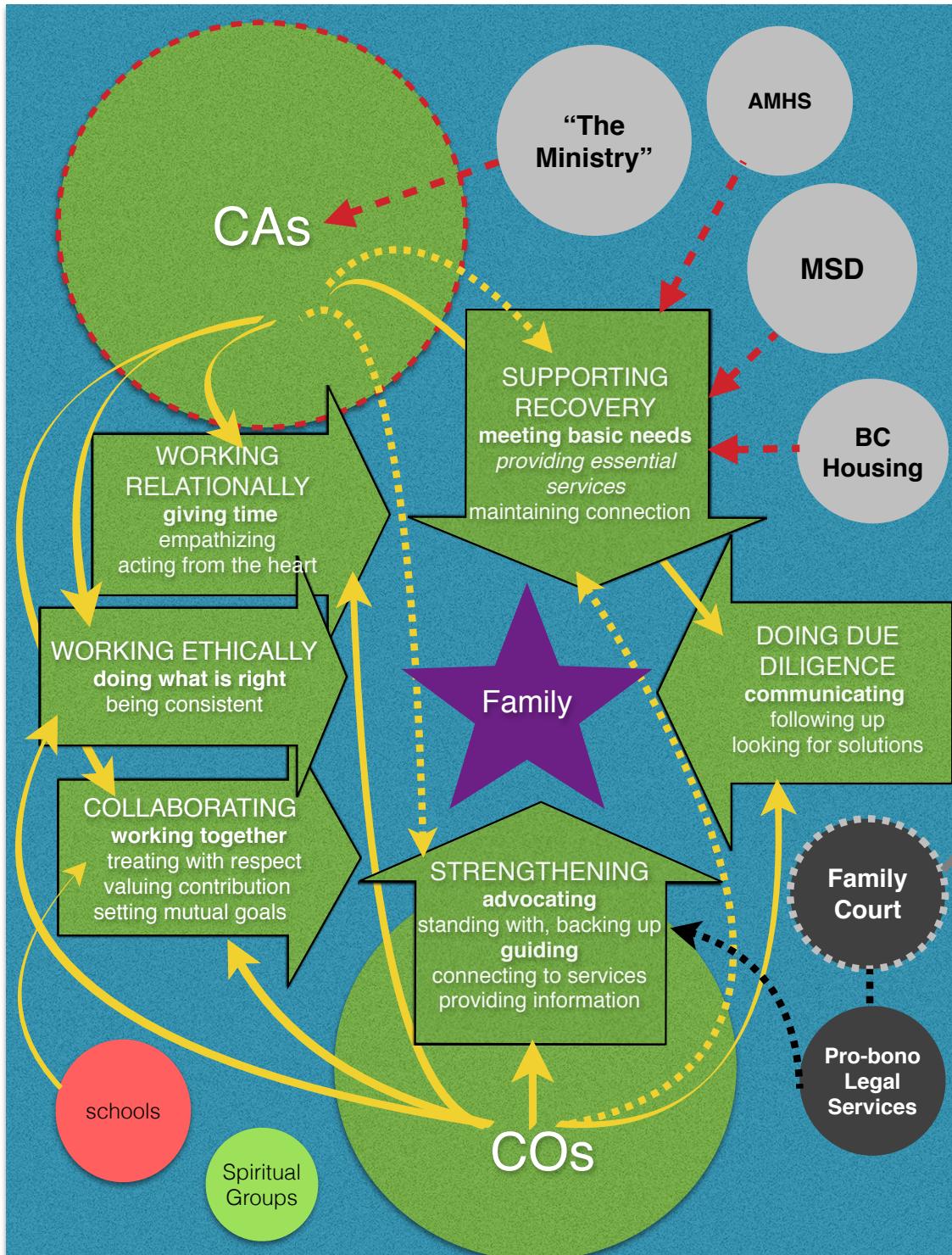


Figure 4: SUPPORTIVE CONTEXT

## SECTION II: TEARING DOWN WALLS - BUILDING BRIDGES

From ‘tearing down’ the system to building relationships — parents made several recommendations for addressing what all saw as significant ‘flaws’ across service domains.

### **RECOMMENDATION 1:**

- **Rebuild “the system” based on the principles of social justice**

### **RECOMMENDATION 2:**

- **Create an integrated services ‘community’**

Some parents spoke of abolishing the current “system” of government services and building a new ‘community’ of services based on the principles of social equality and justice. Parents’s accounts highlighted the need for replacing the current fragmented system with an integrated, coordinated system of supports that could offer a continuum of services to the family.

### **RECOMMENDATION 3:**

- **Address systemic bias against parents with MI and parents coming in contact with government services**
  - **Evaluate operations of Ministries (especially MCFD and MSD) to identify discriminatory practices**

### **RECOMMENDATION 4:**

- **Hold the government accountable for failed promises**

Barring a complete overhaul, parents identified an urgent need to identify and address systemic bias, i.e., protocols and practices that discriminate against parents with MI and parents coming in contact with the system. This was a high-priority recommendation for “The Ministry” (MCFD) and MSD. Additionally, many parents called for public accountability from government agencies for outcomes that clearly did not match publicly stated mandates and goals, such as ‘working for the best interests of the child and family’ or ‘eliminating homelessness’.

**RECOMMENDATION 5:**

- **Expand focus on prevention and recovery supports**
  - Increase availability of supports for parents with MI and eliminate barriers to essential services

**RECOMMENDATION 6:**

- **Increase public awareness of mental illness and supports**

Parents also spoke of ‘changing the lens’ of the current system. Parents strongly urged system providers to expand their focus on prevention and supporting recovery, including: increasing availability and access to safe, affordable, family housing; increasing government income assistance to meet the basic needs of the family (e.g., food, hygiene, clothing, and recreational opportunities for the child); and eliminating barriers to disability assistance and other essential services, such as respite support. Many spoke of the need for ‘publicizing’ mental health: making mental health services publicly visible and accessible and increasing public awareness of MI and appropriate supports.

**RECOMMENDATION 7:**

- **Align approach with “best practices” for working with parents with MI**

**RECOMMENDATION 8:**

- **Provide ongoing training for providers in working with parents with MI**

Parents spoke of the need for system services to standardize their approach and align with collaborative frameworks and “best practices” for working with families affected by MI. Many parents’ accounts highlighted the need for system providers to acquire training (including cross-disciplinary training) and ongoing upgrading of skills related to working with parents with MI and their families.

**RECOMMENDATION 9:**

- Lift restrictions on access to all community-based services

**RECOMMENDATION 10:**

- Strengthen the capacity of the community to support parents with MI and their families

Parents also identified the importance of critically examining the system's relationship to community services, including evaluating the impact of the system restricting access to CAs. The majority felt strongly that lifting restrictions on access to all community-based services and enabling the community to provide essential services would stop the cycle of crises for the family and facilitate recovery. Strengthening community services was viewed by participants as imperative to building a supportive community for parents with MI and families. Overall, participants stressed the need for the parent services context to increase its capacity to serve parents with MI.

"If you're not addressing the parents' needs, there is no healthy child."

— participant

**RECOMMENDATION 11:**

- Improve access to accurate information about services

**RECOMMENDATION 12:**

- Increase coordination within and between government and community services
  - Facilitate the role of hospitals, school, and social work services as 'information hubs'

Within the community domain, parents identified a clear need for improving access to accurate information about available services, including increasing capacity of services to offer referrals. Many viewed improvement as an outcome of increased coordination within and between community and system services. This was highlighted by the rec-

ommendation to facilitate the roles of hospitals, schools, and social work services as ‘information hubs’.

In addition to the importance of building relationships across service domains, parents identified the importance of the parent-provider relationship. Parents encouraged providers to give time to the parents and families and to get to know *them*, not just their files or profiles. Some suggested that understanding the family dynamics and culture (including relationships with extended family members) would increase the relevance of supports. Parents also implored providers not to judge, ridicule, or act out personal bias. They appealed to providers’ compassion and asked them to remember the reasons for becoming helpers. Many parents saw the need for service providers to “do more” to combat the stigma against parents with MI, beginning with the parent-provider relationship.

**“Don’t judge!”**  
— participants

### **RECOMMENDATION 13:**

- **Build relationships with parents and families**

### **RECOMMENDATION 14:**

- **“Don’t judge” — work to combat the stigma against parents with MI**

Parents’s accounts highlighted the importance of eliciting the perspectives of parents with MI to understanding the impact of parenting services on the parent and family and to identifying services’ failures and successes. As one participant offered, “The system is broken for all,” but parents with MI have a unique perspective on “the system” from the intersection of the roles of ‘parent,’ ‘person with MI,’ ‘person with disability status,’ ‘service user,’ (often) ‘parent of a child with special needs’, among others. Many participants spoke of the lack of engagement of providers (either in formal evaluations or informal discussions) with parents with MI regarding their experiences of services and viewed this as responsible for the lack of movement towards necessary changes. All parents expressed the value of having their voices heard by providers, academics and the public and stated this as their primary motivation for contributing to this study.

### **RECOMMENDATION 15:**

- **Engage parents with MI in discussions regarding their experiences of services**
  - **Ensure that their voices are heard and recommendations reflected in service plans**

## **Conclusion**

Key actions identified by study participants as facilitative of the ability of parenting services — community and government — to support parents with MI and their families are as follows:

- *Align the design and delivery of mental health and social services with public health and social justice perspectives and approaches*
  - Focus on preventive and recovery services
  - Provide equitable, public access to all essential services
  - Ensure that essential services meet the basic needs of the parent and family (e.g., safe, affordable housing; food security; respite; psychiatric supports)
- *Critically examine the parent services context for systemic discriminatory and inappropriate practices and eliminate these*
  - Establish an impartial body to oversee system services delivery and provide a safe means for parents to voice concerns
- *Actively target stigma against parents with MI in society as well as within the professional community*
  - Promote public awareness of MI and supports
  - Increase the visibility of mental health services in the community
  - Provide ongoing training in mental health support for service providers
- *Increase capacity of parenting services to offer a continuum of services to the parent with MI and family*
  - Increase ‘on the ground’ collaboration within and between service domains (community and government)
  - Increase availability and accessibility of community-based services

*Including parents as partners in these activities — ensuring that their voices are heard and their recommendations reflected in the service plans — was considered by all participants as imperative to creating a service ‘community’ capable of providing responsive services and facilitating recovery and wellness for the parents with MI and their families.*

The findings of this exploratory study are intended to create interest in research and discussions that engage parents with MI as formal partners in planning, delivery, and evaluations of services for parents with MI and their families.