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Siege and Response: Families' Everyday Lives and Experiences with Children's Residential Mental Health Services (SUMMARY REPORT)

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SUMMARY

Siege and Response: Families' Everyday Lives and Experiences with Children's Residential Mental Health Services

G. Cameron, C. de Boer, K. Frensch, G. Adams

Partnerships for Children and Families Project Wilfrid Laurier University 2003

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Siege and Response: Families' Everyday Lives and Experiences with Children's Residential Mental Health Services

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Introduction

Our purpose in interviewing families who had a child placed in residential children's mental health treatment was to provide insight into the lives and service experiences of these families as they struggle to care for their child and find appropriate services. As we endeavored to code, categorize, and make sense of the information shared with us by families several other more pointed purposes emerged as integral to our efforts. More specifically we became interested in understanding the functioning of children requiring residential mental health treatment before, during, and after treatment with the aim to comment on general patterns of change for these children across these three time periods. Secondly, we also aimed to characterize parents' perceptions of their families' involvement with residential treatment. In particular we address parents' understanding of the services, their relationships with service providers, and parents' perceptions of their children's experiences.

And thirdly, in order to provide a family context for children's difficulties and the ensuing service involvement, we also discuss family functioning highlighting key family patterns under the domains of work, daily life, and relationships. The inclusion of prevalent family functioning patterns also helps us to address the popular notion that children requiring residential treatment come from highly dysfunctional and potentially

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harmful families. Each of these three purposes are addressed in turn in an effort to provide a more complete picture of the families involved in residential treatment and their service experiences. We conclude with some implications for service delivery and thoughts to pursue in future investigations.

This research was conducted under the umbrella of the Partnerships for Children and Families Project. The Project is a five-year (2000-2005) Community University Research Alliance funded by the Social Sciences and Humanities Research Council of Canada. Our research focuses on understanding the lives and service experiences of families and children who are served by children's aid societies and children's mental health services in Southwestern Ontario, Canada. Our purpose is to foster improvements in existing child welfare and children's mental health policies, delivery systems, administration, and programming/interventions.

One of the Project's tenets is to ensure that the voices of parents involved in these services are given a forum in which to be heard. As such, excerpts from actual interviews with parents are included in Project reports to respectfully reflect the real life experiences of families, as well as animate patterns suggested in our analysis of the data. Where appropriate we have also included tables to summarize any emerging dominant patterns. Each section of this summary serves as an overview of the corresponding chapters in the full length research report. For a richer sense of the struggles facing families with a child requiring residential mental health treatment, you can request the full length research report by contacting The Partnerships for Children and Families Project. Research reports can also be downloaded at no cost from www.wlu.ca/pcfproject.

Methodology

Sample

This report is based on information obtained by interviewing 29 primary caregivers who had a child placed in residential care at one of two Ontario children's mental health agencies. There were 27 female caregivers and 2 male caregivers interviewed. The mean age of interviewed parents was 40.75 with a range of 30-54 years. The average number of children per family was 2.93 with a range of one to eight children. Eighty-three percent of parents indicated being born in Canada. Other countries of birth included England, Jamaica, Scotland, Portugal, and the United States. Similarly, 89.7% of parents indicated that English was their first language spoken. Other languages first-spoken included German, French, and Polish.

Indicated length of agency service involvement ranged from one month to 14 years with an average of 1.84 years of agency involvement. Eighty-two percent of parents reported that their child had received agency services for two years or less. In this report, the names of each agency have been changed to Agency Y (Younger) serving children aged 5-12 and Agency O (Older) serving youth aged 12-15 to protect the identity of the agencies involved, as well as offering further protection of the identity of parents interviewed. In addition any other information that could be used to identify parents, children, and families has been changed. This includes, for example, the names of family members, cities in which families live, or specific life circumstances that, when combined, could be used to identify a particular family.

Procedure

The sample was selected by contacting all families who had been involved with either of the two participating agencies over the past two years at the time of our data collection. There were 29 parents who agreed to participate in an interview. Parents were visited in their homes by an interviewer to engage in one-on-one dialogue to explore dimensions of their everyday lives and reflect on their service experiences. Interviews consisted of a series of open ended questions and were approximately 1 ½ to 2 hours in length. All interviews were audio-taped and transcribed. Parents were given a gift of \$25.00 for participating in the study. Following the interview, parents were sent a copy of their interview to keep.

Part 1

Parents' Perceptions of Residential Services

Parents of children requiring residential treatment are seasoned advocates for their children. Prior to considering this extreme option, these parents have negotiated their children and themselves through a range of services explicitly and peripherally connected to children's mental health. These services, such as those offered by children's mental health centers, children's aid societies, psychiatric in-patient and outpatient units, school-based programs, to name a few, are utilized with varying degrees of success. By the time the child is placed on the waiting list for residential treatment, the situation for the child could be described as critical. Parents are exhausted and overwhelmed.

The purpose of this section is to summarize parents' perceptions of residential children's mental health treatment services. This section is not intended to be an

examination of treatment outcomes nor a program evaluation. Rather it offers descriptions of parents' experiences with residential treatment services and the parents' perceptions of their child's experiences. In a broad sense, this summary will elucidate parents' understandings of the service, the relationships foraged between them and the service providers, and the contextual placement of these experiences within in the broader framework of service and support they and their children have received from other sources. In the full length research report, this section is organized chronologically beginning with the child's name being placed on the waiting list and concluding with the child's discharge and the follow-up services delivered post discharge.

In general, parents viewed residential treatment as an extreme treatment option. It was a treatment of "last resort" considered because of the tenacious and escalating nature of their child's behaviour, the ineffectiveness of previous treatment modalities, and parents' mounting difficulties in containing and coping with their child's behaviour. Over half (62%) of the parents first heard about residential treatment as an option for their child from professionals, such as teachers, doctors, and social workers already involved with the family.

Overall, parents were generally pleased with their child's placement in the residential treatment center. Parents felt respected, valued, and understood. They experienced staff as competent, compassionate, and helpful. Residential services offered respite for families and containment for the focal children. Many parents were able to report gains made for themselves and their children. Yet only 17% of parents felt that sufficient gains had been made to warrant the discharge of their child from the center. Parents tended not to blame the residential center for the lack of progress. The also

seemed unable to articulate what the residential center could have done differently. Yet these parents, extremely hopeful when they first had their child placed in residence, had to come to terms with the realization that service outcomes had not matched their hopes. These stories highlight both the complexity and the tenacious nature of these children's mental health difficulties. They also provide a challenge to service providers. What do we do when good is not good enough?

Part 2

Summary of Child Functioning Before, During and After Residential Care

The importance of understanding the long term benefits of residential care for these children and their families emerged from the analysis of these 29 narratives. This section summarizes our examination of the functioning of the focal children before, during and after their involvement with residential care.

General Change Patterns in Focal Child Functioning Across Three Time Periods

For the 15 older cohort children involved in residential care, only five of the responding parents described relatively enduring and positive changes for the focal child after leaving residential care. Of these five, four parents also described important ongoing concerns about the focal child's functioning. Ten parents commented that the focal child's problem behaviours were similar to or worse than prior to entering residential care. Of particular note is that every parent who commented on the focal child's schooling after residential care indicated that the child was no longer in school or at risk of quitting school.

There were only mildly more encouraging general patterns of change for the 14 younger focal children involved with residential across the three time periods. Slightly less than half of these parents commented on significant and continuing positive changes in the focal child's behaviours after leaving residential care. These perceptions of positive change were equally divided between parents who talked almost exclusively about positive changes and those who also expressed concerns about continuing behaviour challenges for the focal child. Slightly more parents [57%] said they did not notice any enduring positive changes for the focal child after leaving residential care with the child's behaviour similar to or worse than prior to entering care. Of particular note is that, of the parents who commented on schooling after residential care, 90% expressed concerns about continuing serious school challenges for the focal child. Also significant is that 46% [6] of the focal children did not return to the same home after leaving residential care.

Child Functioning Prior to Residential Care

<u>Violence:</u> About half of the parent's of the older cohort children in residential care talked about instances of violence by the focal child prior to entering care. The most common target of the violence in these accounts were the mother and siblings of the focal child. Violence towards peers was described in three stories. The overt and dangerous nature some of the violence is striking: a knife was used to attack in 4 stories and threats to kill made in 5 stories. Slightly more than half of the older cohort parents indicated that the focal child had been involved with the police and/or courts prior to entering residential care.

Parents described a marginally higher proportion [66%] of the younger children in residential care engaging in overt acts of violence than the parents of the older children. Equally striking was the intensity of the violence given the relatively young age of the children involved. These stories tell of physical assaults and sexual "inappropriateness", the use of weapons and threats to kill.

<u>Family conflict:</u> About 65% of the older cohort stories emphasized abusive and intimidating behaviours by the focal child towards other family members. Parents described threats, intimidation and physical violence directed towards themselves and others in the home. There was a pattern of the parents and the family wearing down as the behaviour escalated over time.

Almost every younger cohort parent [92%] talked about the extreme consequences the focal child's behaviour was having on their family. These stories are of parents and siblings feeling "terrorized" and "held hostage" by the focal child. Physical attacks, extreme temper tantrums and rages were common themes.

Personal functioning: About half of the older cohort parents talked about "anti-social" and delinquent behaviours by the focal child including hanging out with delinquent peers, running away from home, not going to school, substance abuse as well as aggression and violence. All of the younger cohort parents talked about the challenge of coping with the personal functioning challenges of their focal children. Younger cohort parents talked about hyperactivity and prolonged bouts of angry, aggressive and even violent behaviours. A common refrain was expressed by one parent as "waiting for a bomb to explode".

School: About two-thirds of the older cohort parents talked about their focal child's school problems. The portrait was quite similar across stories: acting out in the classroom and with teachers and peers, irregular or no attendance, and academic failures. Suspensions, expulsions and grade failures were the norm in these stories. About 80% of the younger cohort parents' anecdotes highlighted their focal child's difficulties in school. A clear portrait emerges from these stories of children failing seriously in their schooling to the point that staying connected with the "regular" school system seemed impossible. Many of these parents pointed to serious impediments to their child's learning as well as to significant behaviour problems at school. Suspensions from school were commonplace.

Social involvements and substance abuse: One third of the older cohort stories highlighted that the focal child was drawn to and associated frequently with "delinquent" peers and "street kids". The parents of younger cohort children involved with residential care also emphasized the struggles their children had relating to friends and peers. *Child Functioning During Residential Care*

Sixty percent of the older cohort parents saw modest or no positive improvements in the focal child's functioning while in residential care. Five parents talked about their child running away, sometimes repeatedly, from residential care and four parents mentioned that their child did not stay as long in the program as desired by program staff. Only three parents talked mainly about positive changes in their child's functioning during the placement, while five noted some positive changes coupled with enduring child functioning challenges.

Eighty percent of the younger cohort parents pointed to some positive changes for the focal child while in care, with 50% of parents talking mostly about positive changes for the focal child. Sixty percent of these parents suggested that these were welcome and major changes in their child's functioning. Thirty percent of parents saw little or no positive change for the focal child while in care. A particular point of contrast with the older cohort children is that only one child ran away from the residence while in care and no parent talked about their child leaving care before program staff desired.

Child Functioning After Residential Care

While three-quarters of older cohort parents pointed to some positive attitudinal and behavioural changes for their children, 80% of these parents clearly saw these gains within the context of continued major difficulties for their child. Two thirds of the older cohort parents talked about very serious problems for the focal child after leaving care including crime and delinquency, substance abuse, running away from home and "living on the streets", aggression and violence and major non compliance with family "rules" at home.

While the general assessments by younger cohort parents of the functioning of their child after leaving residential care are moderately more positive, only four younger cohort parents' stories emphasized mainly the positive gains made by their child since entering care. And in each of these four stories, there were descriptions of ongoing child functioning challenges which required special attention. Almost 60% of the younger cohort stories emphasized very serious continuing challenges for the child after residential care. Of particular note is that almost half of the younger cohort children leaving residential care did not return to live in their original home.

Concluding Comments for Child Functioning Before, During, and After Residential Care

These stories provide dramatic testimony that most of the older cohort children in this study leaving residential care had very serious ongoing problems in daily living. Problems which in many cases rival or exceed the challenges faced prior to entering residential care. About one-third of these children had left home and many had unstable living arrangements or were "on the streets". Notwithstanding moderately more evidence of "successful" or partially "successful" adaptations, the after care daily living portraits of younger cohort residential care graduates were not notably more encouraging. About half of these younger children did not return to their original homes after residential care. Serious areas of concern shared by both groups of children include continuing major adaptation problems at school and continued high levels of pressure on the parents and siblings of many of these children.

A central question emanating from this study is what can be expected for these children - in school, employment and relationships - over the years ahead. These findings suggest that a short or moderate term stay in residential care is not a sufficient intervention for most of these children. The development of variations in living arrangements for these children, enhancing school and employment opportunities, and building continuing support to these children and their families with the challenges of daily living merit serious attention.

Part 3

Summary of Family and Parent Functioning

Caring for the focal child permeates every facet of daily life for these families including work, health, and relationships. Parents experience prolonged elevated levels of daily stress trying to balance daily "routine" and the needs of family members with caring for the focal child. Family climate is markedly tense and frequently involves conflict, particularly with the focal child. Relationships among other family members suffer as well, with parents reporting increased marital strain and little time to devote to siblings of the focal child. Caring for the focal child is taxing on parents' physical and mental health with parents reporting depression, insomnia, and physical illness. Given the effects on other family members of caring for the focal child and the amount attention and resources investing in parenting this child, perhaps the clearest areas of benefit from these residential placements, at least in the short run, are for family members other than the focal child.

Our research indicates that about half of these families and parents return to relatively "functional" ways of living when the immediate pressures of living with the child placed in residential care are relieved. Other parents and families are best characterized by various levels of ongoing struggles. The description of life in the home prior to the focal child entering residential care, however, was indistinguishable between these two groups of families. What emerges is a mixed image of these families and parents. While a little less than half of these focal children are described as having experienced potentially "traumatic" events within their nuclear family, there is little suggestion that many of the focal children themselves have been the object of sexual

abuse or ongoing physical abuse. As such, we suggest caution in emphasizing family functioning as sufficient or primary catalysts for the behaviours of the focal child.

Part 4

Summary of Child Functioning Over Three Selected Developmental Periods

Several questions arose for us as we began to analyse the data. Who are the children represented in the sample? How are we to understand their difficulties? Why do they behave as they do? Why are treatment outcomes so poor? It seemed that the focal children represented in the sample were a diverse group. They came from a variety of families ranging from intact two parent families to single parent families, step-families, adoptive families, foster families and extended families. There was a range of family functioning, income levels, and levels of education. Of the children who received diagnoses there was also variety, including: Tourettes Syndrome, ADHD, Fetal Alcohol Syndrome, Central Auditory Processing difficulties, Bi-polar disorder, Depression, Autism, Obsessive Compulsive Disorder, and Conduct Disorder. In sum, no single profile emerged. We were struck by the seeming paradox between a very complex and dissimilar group of focal children and a uniform and invariable treatment modality. How could one approach, namely a psycho-educational model with a cognitive behavioural focus, be able to address the needs of such a diverse group? Are residential treatment centres being expected to accomplish too much?

In our attempts to better understand the focal children, we decided to "dig a little deeper". We began to amass the clues contained within their stories which could help us achieve that end. Ultimately, we knew that the data could not provide us with concrete

answers. However, we were confident that we could provide a foundation for intelligent questions and speculation. This chapter is organized around some key observations with relevant data and analysis grouped accordingly. But first a note with respect to the strategy used in collecting and organizing the data.

All references to child functioning in the twenty-eight¹ transcripts were catalogued according to three selected time periods. The time periods were chosen because they correspond with primary developmental challenges and social transitions. The first time period extends from the focal child's birth to his/her entrance into school at ages 4 or 5. During this time period behavioural challenges are often limited to the child caring environment, usually the family and in a few instances supplemented by home child care providers and daycare centres. In this first time period the child's social network is quite small. The second time period covers the primary school years from ages 4-5 to 12. The child's social world has broadened. The child's functioning is evidenced in a larger arena under the purview of teachers, peers, and social groups such as beavers, guides, recreational sports teams etc. The child's ability to respond to academic and social challenges can begin to be observed in this time period. The third time period stretches from ages 12 to 17 - 18 and covers the middle school and high school years. This period begins with the transition from primary school to middle school and covers the social challenges of adolescence, puberty, and the broadening of the child's social world to include the larger community.

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¹ Twenty-eight of the twenty-nine cases were included in this analysis because for one case, the respondent was a foster mother who had little to no information about the child's early history.

Using all the catalogued references to child functioning, we created an overview of the three developmental periods for each child. We wondered if, looking across children, patterns of behaviour would emerge for each developmental period. For example, we wondered if we could capture or "snapshot" a pre-primary school profile or a middle school profile. We discovered we could not, given the variability and complexity across cases. However, what we do have is a graphical representation of child functioning across the three developmental periods (See Figure 4.1–Younger Cohort and Figure 4.2–Older Cohort).

The references to child functioning were sorted into one of four categories (refer to the legend accompanying Figures 4.1 and 4.2). If the child's functioning was not identified as a problem, the functioning was represented by a grey line. If the child's functioning was considered problematic but still manageable, it was represented by a dotted line. If the child's functioning was considered problematic and unmanageable, it was represented by a solid black line. Significant events, such as incidents of abuse, parental separation, trauma, loss etc., were marked by a solid black dot. If we did not have information about the focal child for a specific time period we recorded that with a thin black line indicating "No Data". We were now able to see the data in a new way and we were able to make several broad observations with respect to the behavioural profiles of the focal children.

It should be noted that it is difficult to map out temporal sequences using qualitative data. The intent of this exercise is <u>not</u> to generate precise chronologies of each child's functioning. Rather the intentions are to look at broad behavioural patterns for these children, to note the developmental transitions which may be difficult for these

children to traverse, and to observe when behaviour peaks and wanes and note any corresponding environmental factors. Ultimately, the observations made will challenge our understanding of the presentation and genesis of the focal child's behaviour.

Patterns from the two figures suggest that despite the similarities in behaviour of these children, they have unique profiles of a variety of problems, life histories and family environments. It can be argued that these children arrive at a similar point from many different trajectories. We acknowledge that this data is insufficient for us to make any claims with respect to etiology of the focal child's behaviour. The data was not collected with this intention in mind. However, these profiles are different from each other in that individual children's behaviours are peaking and levelling off in different developmental periods and certainly is suggestive of distinct etiologies.

The figures also suggest that the children represented in the older cohort sample have different behavioural profiles than the children represented in the younger cohort. The older cohort, when they were the ages of the younger cohort exhibited more manageable behaviour. What this suggests is that the older cohort children were not like the younger cohort children when they were the same age and at their stage of development. This is an important observation because it highlights the alarming and perhaps more disturbing behaviour of the younger cohort. They exhibit extreme problematic and unmanageable behaviour similar to the older cohort, but years earlier up to twelve years earlier in some cases. We can understand the behaviour of the older cohort as being somewhat typical of adolescent behaviour albeit atypical in it extreme, inimical, and violent presentation. But when we observe this same behaviour in children in their pre-primary and primary school years and note the same extreme, inimical, and

violent presentation we can no longer cling to any type of developmental supposition. We expect children in their pre-primary and primary school years to be "manageable" and submit to the authority structures of home and school.

We are left with many questions related to the futures of the younger cohort children and the progression of their behaviour. Their problems and struggles seem far from over and they have yet to hit puberty, the transition from middle school to high school, and the transition from adolescence into adulthood. How will they handle these upcoming challenges?

Concluding Comments for Child Functioning Over Three Selected Developmental Periods

Popular understandings of extreme unmanageable behaviour in children tend to fall into one of several possible categories: the behaviour is attributable to family dysfunction and poor parenting; the behaviour is symptomatic of a mental illness; or, the behaviour is a reaction to trauma. Indeed, there are children represented here for whom one or more of these understandings is salient. However, our findings challenge these understandings as much as they support them. In essence, when it comes to understanding the behaviour of the focal children, both its presentation and its genesis, these stories raise as many questions as they answer. These stories challenge the notion of a single or root cause of extreme unmanageable behaviour. Instead they offer a complex and unsettling portrayal of these children, their familial and social environments, life histories, their strengths and challenges.

Conclusion

In general parents viewed residential treatment as an "extreme" treatment option; a "treatment of last resort" merited by the tenacious and escalating nature of the child's behaviour, the ineffectiveness of previous treatment options, and parents', schools', and communities' mounting difficulties in containing and coping with the child's behaviour. Despite this perception, 73% of parents reported feeling positive about residential treatment after their initial involvement and this feeling was largely sustained throughout the duration of the treatment. Undoubtedly the initial positive regard is linked to the immense relief families experience as the immediate pressure of caring for the focal child is eased when he or she enters residential care; however, the endurance of this affect speaks to the solid efforts of program staff in their delivery of services. Juxtaposed with the relatively poor outcome patterns for children leaving residential care, this positive view of residential treatment held by parents long after treatment ends is perplexing. Indeed most of the older cohort children in this study leaving residential care continued to experience serious ongoing problems in daily living which in many cases rival or exceed the challenges faced prior to entering residential care. About one-third of these children had left home and many had unstable living arrangements or were "on the streets". The after care daily living portraits of younger cohort residential care graduates were not notably more encouraging, albeit there was moderately more evidence of "successful" or partially "successful" adaptations for this cohort. About half of these younger children did not return to their original homes after residential care. Serious areas of concern shared by both groups of children include continuing major adaptation problems at school and continued high levels of pressure on the parents and siblings of many of these children.

The pattern of family functioning that emerges from this investigation raises the proposition that, given the burden on other family members of caring for the focal child and the "disproportionate" share of attention and resources investing in parenting this child, the lives of other family members must be given equal value in determining the benefits of helping interventions in these situations. Perhaps the clearest areas of benefit from these residential placements, at least in the short run, are for family members other than the focal child. These are important considerations, given the incredible pressures families manage when the focal child is at home, and the extreme disruptions in family life described in these stories. In light of the problems many of these children continue to have after leaving residential care, not returning home may be a preferable outcome in some of these stories.

We must also beware of valuing only the well being of the child and neglecting the often extreme costs mothers in particular pay over many years in caring for and seeking assistance for their child. In our research, the burden of caring for the focal child fell primarily upon mothers and the levels of pressure faced by these women, typically over many years, are striking. In considering the impacts of residential children's mental health treatment and potential improvements in helping responses, there are good reasons to be concerned about the consequences for the well being of mothers/parents going through such trials. We also question the reasonableness of parents and family being "expected" to pay these kinds of prices on their own as part of a "normal" entitlement they owe to their child.

Earlier data showed that about half of families returned to lower stress levels and more functional relationships within the home when the focal child was out of the home. The balance of families, while reporting lower levels of stress and improved relationships, described continuing struggles at home while the focal child was in residential care. For parents, in particular, approximately half talked about substantial improvements in their own emotional well being when their child was in residential care or out of the home while others described a long and continuing history of "emotional" challenges. What emerges is a mixed image of these families and parents. It is significant that in our research the description of life in the home prior to the focal child entering residential care was indistinguishable between these two groups of families. It is also important to highlight that, in our research with families involved with child welfare services, the "norm" was for descriptions of much more disrupted family and parent lives than in this residential care study. Yet there is no parallel in these stories to the unrelenting pressures parenting the focal child represents nor to the children being so impermeable to efforts to help.

An obvious question emanating from these stories is what can be expected for these children - in school, employment and relationships - over the years ahead. This study suggests that the younger cohort will continue to struggle as they face new challenges associated with the transition into middle school and high school. There were few children engaged in the regular school system with many children functioning academically at a lower grade level than their same-aged peers. For the older cohort, employment opportunities and the transition into adulthood will present added challenges. As such, we highlight the distinction between pursuing "cure" and "care"

objectives for these children. There is almost no support in our study for helping strategies predicated on "curing" or changing the focal child through short-term or medium-term interventions [e.g. improved social skills, better anger control, new coping strategies] so that he or she can prosper in everyday family, school and community environments. If improved long term outcomes for these children and their families are a priority, these stories indicate that our attention could profitably turn to the creation of an ongoing continuum of care between residential care and living within a family unit or independently. Variations in living arrangements, enhancing school and employment opportunities, and continuing support to these children and their families with the challenges of daily living merit serious attention.