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Elizabeth Fenzel
Parents' and Caregivers'
Experiences with their
Children's Residential
Treatment Centers

ABSTRACT

This study explored the experiences of parents and caregivers at their child's Residential Treatment Centers (RTCs). Family involvement has been widely accepted as a factor that benefits children in RTCs and family centered practice encourages parent participation in all aspects of a child's care, yet there is limited research on parents and caregivers' participation in two key areas at RTCs: the day-to-day care of their child and the treatment planning/implementation for their child. Thirty-four parents and caregivers of children in RTCs completed a mixed method survey which asked respondents to identify how they are or are not involved in the day-to-day activities and treatment planning/implementation of their children and their level of satisfaction with aspects of their involvement, including amount of involvement, decision making opportunities and interactions with daily care and clinical staff. Respondents also shared barriers and supports to their involvement, the impact their involvement in RTCs has had on their child and their families as well as advice they would give families and RTCs about involving families. The findings indicate that parents and caregivers have a range of involvement at RTCs and that they are more satisfied with higher levels of involvement, increased opportunities for decision making and when they have collaborative, supportive relationships with staff. Recommendations for enhancing family involvement practices at RTCs as well as suggestions for future research are discussed.

PARENTS' AND CAREGIVERS' EXPERIENCES WITH THEIR CHILDREN'S
RESIDENTIAL TREATMENT CENTERS

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2010

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CHAPTER I

INTRODUCTION

Children are part of families and when they become sick, they remain parts of families. Families are integral to the healing process of their children. They provide emotional support, encouragement, and love as well as practical support such as family history and intimate knowledge of a child's behaviors, strengths, fears, preferences, and dreams.

Despite the undeniable connections between families and their children and the health benefits that arise from these connections, mental health facilities have traditionally treated the child in isolation with families left in the waiting room or at home. With the rise of family centered principles, however, this practice is beginning to shift. In health care and mental health facilities across the country, administrators and practitioners are developing treatment guidelines and programs that capitalize on the beneficial connections between families. Families are seen as having inherent strengths to offer their child, the capacity to gain additional tools to support their child, and the right to make decisions for their child.

Residential Treatment Centers (RTCs) represent a unique and challenging setting to apply family centered principles. To gain access to the intensive services and supervision that their children's severe emotional and behavioral disorders require, parents must send their children away from home, so that families experience separation.

Often, these specialized facilities are located far from home, making ongoing contact difficult for both parents and the facilities to manage. Since the children live at these facilities for long periods of time, from several months to years, it becomes difficult to navigate who is in charge of the child. For practical reasons, staff are required to take over many parenting functions, from dressing the children, to feeding them, to providing homework help and putting them to bed. Furthermore, the children need the services of these professionals and require the intensive support that the parents do not have the training or time to provide. Finally, the fact that the child has a mental illness often carries a stigma that the parents are to blame or are part of the problem, further compounding the parents' sense of isolation when they are already separated from their child.

The inspiration for this study came from my experience working with children and their families at an RTC in California. I learned from these families the limitless love that a parent has for their child and the unyielding yearning that a child has to be connected to their parents. I saw how a parents' devastation regarding their child's illness and loss of hope due to a system that had repeatedly failed them were too often misinterpreted as resistance and lack of cooperation. I was humbled when I experienced the appreciation of a parent who for the first time felt respected and welcomed by a mental health professional. Finally, I experienced the power in partnering with a parent in the care of their child, which led to numerous moments of mutual support, creativity and innovation, always to the benefit of the child. In my work, I was consistently awed by the many brave families I met, who faced seemingly insurmountable challenges with grace and determination, motivated by the love of their child. I was honored to join these

families at a vulnerable time in their journey and work with them to build a renewed sense of hope toward a brighter future for them and their child.

The research on the benefits of family involvement in residential care confirms my own experience working with children and families in these facilities. As the summary of the literature in the next chapter will demonstrate, children do better when they have family involvement during their stay in residential care. While efforts have been made to increase family involvement and move towards family centered models at RTCs, research suggests that the implementation of family involvement programs varies widely. Issues such as negative staff attitudes towards family involvement and a lack of consensus on collaborative decision making have impacted the effectiveness of family involvement programs.

Furthermore, although the literature on family centered residential treatment programs encourages family involvement in all aspects of the child's day-to-day care and treatment, the research has not been able to capture the breadth of family involvement at RTCs since it has typically limited its investigations to parents' participation in family therapy and contact with their child. Little is known about the types of contact the parents are having or the multitude of ways that parents and caregivers could be and are involved in the day-to-day activities and treatment of their child. These areas are particularly important to study since they would likely involve high levels of interaction and negotiation with direct care and clinical staff and would provide valuable feedback to mental health practitioners and RTC administrators to improve staff-parent relationships and enhance collaborative decision making practices with families.

This study explores the experiences of parents and caregivers at their child's Residential Treatment Centers (RTCs) and the current state of family involvement practices in these facilities by focusing on two relatively unexplored areas of involvement, parents and caregivers' participation in the day-to-day care of their child and the treatment planning/implementation for their child. Through a mixed-method survey, parents and caregivers of children in RTCs were given a voice to explain how they were or were not involved in these areas as well as their satisfaction with their involvement, including their experiences with decision-making and staff interactions. The study also considers how certain factors, such as staff attitudes, barriers and supports and demographic variables related to the RTC, child and child's placement, might influence or affect parents' level of satisfaction and amount of involvement. Finally, the study asked parents to describe the impact their involvement in RTCs has had on their child and their families as well as advice they would give families and RTCs about involving families.

Since the implementation of family involvement programs varies among RTCs, this study aims to illuminate the diverse experiences of parents and caregivers at RTCs across the country. This will deepen our understanding of how parents feel some residential treatment centers are or are not currently involving families as well as what is impacting their involvement. RTCs can then use this information to more effectively and sensitively work with families, which, in turn, would strengthen the treatment that they provide youth. By considering family involvement from a family's perspective, we ensure that their voices are heard, a key tenet of family-centered approaches in mental health care and critical to developing programs that make sense for families.

The methodology of the study, including the selection of the subjects and the survey procedures are discussed in Chapter III, the findings are discussed in Chapter IV, and the discussion and conclusion of this study are presented in Chapter V. The history and evolution of family involvement at Residential Treatment Centers, current trends in family centered care as well as pertinent research on family involvement at these facilities are discussed next in Chapter II, the Literature Review.

CHAPTER II

LITERATURE REVIEW

This chapter will review the literature on family involvement in Residential Treatment Centers, including a brief history of Residential Treatment Centers followed by a summary of the benefits of family involvement in treating children in RTCs, the history and evolution of family involvement practices at these facilities leading to a shift toward family centered care, and the relevant research on family involvement practices at RTCs throughout the country.

A History of Residential Treatment Centers

Residential Treatment Centers (RTCs), specializing in the treatment of children with emotional problems, came into existence in the 20th century. The origins of many of these facilities were sectarian institutions that provided long-term custodial care and shelter to orphans. Influenced by the rising use of psychoanalysis for the treatment of children in the beginning of the century, RTCs began to implement therapeutic group care programs, staffed by professional child care workers and psychiatrists, and focused on the treatment of children instead of simply providing them with housing and supervision. By the 1950s, RTCs had become a specialized facility providing psychiatric care and mental health treatment to children with the most severe emotional problems (Maluccio & Marlow, 1972).

In the 1970s and 1980s, shifts in mental health care, including deinstitutionalization and the increasing emphasis on serving the family, not just the child

in isolation, led to the development of community and home based alternatives to institutionalized care. RTCs then became part of a continuum of care for out-of-home placements. These out-of-home programs range in restrictiveness from the least restrictive, treatment foster care and community based group homes, on one end to the most restrictive, psychiatric hospitalization, on the other end with RTCs being the second most restrictive provider of care (Lyman & Campbell, 1996; McCurdy & McIntyre, 2004; Pierpoint & McGinty, 2004).

RTCs are defined as a “licensed 24-hour facility (although not licensed as a hospital), which offers mental health treatment” (Satcher, 1999). RTCs are usually unlocked, but a few are locked like inpatient psychiatric hospitalization units. RTCs are distinct from inpatient psychiatric hospitalization, however, due to the longer duration of stay of clients from several months to a number of years and the majority of treatment staff being non-medical personnel. Unlike the community based, home-like atmosphere of a group home, RTCs are usually housed in a distinct "campus" that is apart from the community and in which the majority of the child's daily programming, including school, is held (Lyman & Campbell, 1996, p. 8).

While approximately 20% of youth ages 9-17 have a diagnosable emotional or behavioral disorder, less than 1% of young people in this country reside in out-of-home care. Of the youth in out-of-home care, 15-30%, or approximately 50,000 children, live in Residential Treatment Centers (Whittaker, 2004; Bazelon Center, 2004). Although only 8% of all children receiving mental health treatment live in RTCs, nearly 25% of national spending on children's mental health is spent on these facilities (Satcher, 1999). These children increasingly represent the most severe cases whose behaviors and illness are

"considered to be so extreme...that their ability...to succeed within more normalized, community based environments (e.g. family, the school) is severely compromised" (McCurdy & McIntyre, 2004, p. 138). RTCs serve as a protected, structured environment that can serve as a step-down program to avoid recurrent hospitalization and can treat children who have had multiple, unsuccessful out-of-home placements (McCurdy & McIntyre, 2004, p. 138; Pierpoint & McGinty, 2004, p. 152).

Benefits of Family Involvement in Residential Treatment Centers

Family involvement has been widely accepted as a factor that improves treatment outcomes of children and adolescents in residential treatment centers. Although research into the effectiveness of Residential Treatment Centers (RTCs) has found high incidences of recidivism (Asarnow, Aoki & Elson, 1996; Satcher, 1999), family involvement has proven to help youth maintain what they have achieved during their stay in residential treatment (Cafferty & Leichtman, 2001; Frensch & Cameron, 2002; Hair 2005). For example, family involvement leads to improved adaption post-discharge (Taylor & Alpert, 1973), more stable discharge placements (Landsmen, Groza, Tyler & Malone, 2001) and lower levels of recidivism (Lakin, Bramblia, & Sigda, 2004).

Not only does family involvement help youth after they have left residential treatment centers, several studies have also highlighted the impact it has during treatment. Higher levels of family involvement have been shown to lead to behavior ratings improvement and academic gains in youth (Prentice-Dunn, Wilson, & Lyman, 1981) as well as reduced symptomatology and increased functioning (Knorth, Harder, Zanberg & Kendrick, 2008; Leichtman, Leichtman, Barber & Neese, 2001). Overall, these studies indicate that family involvement, in the form of perceived support, visitation, and

participation in family therapy, lead to better outcomes for youth during and after treatment.

Family Involvement in Residential Treatment Centers:

From Consumers of Therapy to Decision Makers

A review of the literature for the past 30 years illustrates that there is no universal definition of family involvement in residential treatment centers (Curtis & Singh, 1996; Whittaker, 2004). In fact, what is considered family involvement has expanded over time. Leichtman (2008) describes an evolution of what has been considered family involvement in residential treatment centers as beginning with family therapy, growing to include education and support groups for parents, and finally involving parents on their child's treatment team from admission through discharge (p. 195). In other words, over time, RTCs' focus shifted from seeing the families as recipients of services, such as therapy or training, alongside their child, to viewing parents as partners who collaborate with treatment providers on behalf of their child.

James Whittaker, Ph.D., a leading scholar on residential treatment of youth, strove to fill the gap in the literature that he saw existed regarding ways to effectively work with parents in a group care setting. In his writings on family involvement, he encouraged expanding the definition of family involvement beyond “clinical treatment” of parents (Whittaker, 1979, p. 138) to also include parent education and parent support groups. In addition, Whittaker (1979) introduced the idea of inviting parents to take part in the “life-space” of the program, or the day-to-day activities that their child was experiencing. For example, Whittaker (1979) suggested that parents could observe the program and treatment sessions, join group events and meals and become more active participants in

their child's care by “serv[ing] as consultants” in certain parts of the programming from “menu planning [to] furniture buying” (p. 147).

Jenson and Whittaker (1987) then encouraged the further expansion of parents' role in the RTC, moving beyond their participation in the day-to-day activities of their child to become more active in their child's treatment process. The authors suggested that staff solicit parents' input regarding their child's behavior and history and that treatment plans be written and agreed upon by the child and family members. Parents could also be encouraged to become involved in treatment implementation as they can be called to help solve specific behavior problems. Further, parents would be given more responsibility in the day-to-day activities of their child, such as purchasing clothing for him or her and being allowed to decide the child's chore schedule. Instead of parents being considered consumers of therapy or recipients of training, they could begin to have an active role as valuable contributors to their child's treatment. Other researchers agreed, citing the benefits of having family participation beyond isolated moments, and instead encouraging families to be involved in all aspects of the RTC from the beginning of treatment through discharge (Curtis & Singh, 1996; Fairhurst, 1996).

As the new standards for family involvement expected families to take a more active role in both the daily activities of their children and the treatment planning and implementation, the issue of family involvement in treatment decision-making came to the foreground. Some authors have described parents' participation in decision making as occurring later in treatment, once they have taken part in training and observed the staff working with their child. After the parents have developed and practiced the skills they will need when their child returns home, they are empowered to make more decisions

regarding their child's care and treatment (Fairhurst, 1996; Goyette, Marr & Lewicki, 1994; Martone, Kemp & Pearson, 1989). McNown Johnson (1999) saw the possibility for families to make decisions in numerous areas of their child's day-to-day care, such as purchasing clothing, taking children to doctor appointments, attending school conferences and treatment meetings. In addition, s/he suggested families could actively determine aspects of their child's treatment, such as setting goals of placement, use of medication, how visits will occur and how to handle major discipline problems.

The Emergence of Family Centered Residential Care

This expanding definition for family involvement and emphasis on increased decision making coincided with efforts in mental health care, including residential treatment, to become more "family centered." Family centered care sees the family, not just the child, as the unit of attention for service, focuses on fostering families' strengths and emphasizes the right of families to be involved in decision making. Furthermore, families are understood as doing the best they can with the resources available to them, as being capable of change, and valued and respected by service providers (Allen & Petr, 1996; Villiotti, 1995). Allen and Petr (1998) further described families' right to be "the ultimate decision making authority" (p. 9) in their child's care and to have "informed choice" to decide who is in their family, how decisions are made, how much information to share and how they want to work with a professional to meet their stated needs.

Ainsworth (1998) offered a model to take these family centered concepts and apply them to group care, including residential treatment. The author stated that "family centered group care...is characterized by institutional structures, services, supports, and professional practices designed to preserve and, whenever possible, to strengthen

connections between children in placement and their birth parents and family members” (Ainsworth, 1998, p. 59). On a program level, agencies would offer tangible services that would make it easier for parents to participate such as providing transportation as well as specific training programs to increase parents' skills to reunite with their child. The agency would also involve parents by giving them “access to all information about their child and full participation in decision making about their child’s care, treatment and education plans including spiritual affairs” (Ainsworth, 1998, p. 60). Finally the “attitudes of staff” in the agency would promote “parental access to and connection with the child” (Ainsworth, 1998, p. 60).

Walter and Petr (2008) also offered a framework to implement family centered care in residential treatment, highlighting three central elements: “maximizing regular contacts between child and family, actively involving and supporting families in the treatment, and providing ongoing support and aftercare once the child returns home” (p. 12). Some suggestions for involving families in treatment included having family members serve on agency boards, hiring a family advocate at the agency, and offering quality family therapy and support groups. Parents could also be included in “all planning procedures including permanency planning, goal setting, [and] decisions regarding home visits” (Walter & Petr, 2008, p. 13). Agency staff could “regularly share information” with parents and treat them as “experts and partners,” while being culturally sensitive and creating treatment plans and transition plans that made sense for their families (Walter & Petr, 2008, p. 13). While these experts have supported these principles in theory and have suggested how RTCs could apply them, there has been minimal research to demonstrate how broadly accepted these concepts are at RTCs across the country.

Examples of Family Centered Programs

In the limited data on the implementation of family centered principles at RTCs, there are accounts of four facilities that have begun family centered programs. These agencies have developed a wide-array of family involvement activities including parent education and support groups, structured family activities, parent advocacy, intensive family therapy, inclusion in milieu activities, child/family team meetings, and involvement in the creation, implementation and revision of treatment plans (Bass, Dosser & Powell, 2000; Knecht & Hargrave, 2002; Pierpoint & McGinty, 2004). Overall, these programs were successful, leading to decreased lengths of stay (Knecht & Hargrave, 2002) an increased sense of "involvement, ownership, voice and access" among parents (Bass et al, 2000, p.132), and improved post-discharge stability (Pierpoint & McGinty, 2004).

Alwon et al. (2000) studied a specific program designed to help multiple RTCs in North and South Carolina become more family centered. Like the RTCs above, this program focused on viewing parents as partners and seeing families as having "potential and strengths"(Alwon et al., 2000), leading to a number of systemic changes at the RTCs, including the creation of family-friendly admissions handbooks and the establishment of parent advisory committees. While families were satisfied and children benefitted from these family centered changes, staff initially showed resistance to these new programs, a challenge also highlighted in another program narrative (Knecht & Hargrave, 2002). The issue of staff resistance to family involvement was also illustrated in a study by Baker, Heller, Blacher and Pfeiffer (1995). The authors found that staff were supportive of engaging families in activities that "put staff in a helper role," such as providing parents

with guidance or therapy but were least supportive of activities that “empowered families” such as decision making or direct participation in the residential unit’s daily activities (Baker et al., 1995, pp 64-65), which are key elements of family centered programs. In the study, Baker et al. (1995) surveyed direct care staff, professionals and administrators and compared support for family involvement based on having a professional degree. Those staff with a professional degree were found to be more supportive of family involvement than staff without a professional degree, but the study did not distinguish the type of professional degree and the impact that might have on support for involvement.

Assessing Family Involvement in Residential Treatment Centers

Due to its widely accepted benefits for children in residential care, there have been a number of investigations into family involvement practices at residential treatment programs in the past twenty years. These studies have analyzed the prevalence of family involvement, the effectiveness of family involvement efforts and the influence of various factors on parent involvement at RTCs. By defining family involvement in different ways and obtaining information on family involvement from multiple perspectives, each of these studies has begun to build our understanding on the current state of family involvement practices at RTCs as well as how these programs can be further enhanced.

Defining and measuring family involvement

Despite the expanding definition of family involvement in the literature and within certain residential programs, much of the research into family involvement has either narrowly defined it or isolated certain aspects of family involvement to study. Some studies have focused on therapy, including the prevalence of family therapy

(Edwards, 1991) and parents' perceived benefits from telephone therapy (Springer & Stahmann, 1998). Others have explored the implementation and effectiveness of various training programs (Carlo, 1988, 1991, 1993; Carlo & Shennum, 1989; McCurdy & McIntyre, 2004; Modlin, 2003). More recent studies have measured the prevalence of "family involvement," but narrowly defined their involvement as contact between children and their families by phone or visits (Robinson, Kruzich, Friesen, Jivanjee & Pullmann, 2005; Nickerson, Brooks, Colby, Rickert & Salamone, 2006).

In contrast, some investigations into family involvement do consider a wider definition when measuring family involvement. Baker, Blacher and Pfeiffer (1993) surveyed staff at three RTCs that served a total of 234 children, measuring the level of family involvement by frequency of telephone contact, visits to the facility and home visits as well as participation in social and educational activities and analyzed this data using comparisons based on demographic data from the families. They found that the level of family involvement was highest when the family lived near the facility and was of higher socioeconomic status and when the child was younger and had fewer behavior problems. They also found that there was low level of involvement with families, with nearly 33% of children having no visits with their families and 50% having three or fewer visits per year (Baker et al., 1993, p. 565).

In her measurement of family involvement, McNown Johnson (1998) expands the definition of family involvement even further to include family centered concepts, such as shared decision making between staff and parents about the treatment and day-to-day care of their child as well as participation in case planning. In her study, she compares the experiences of parents who voluntarily placed their children and parents who were

mandated by public agencies to place their children. She found that families of privately placed children were more likely to have equal say with staff in making decisions about their child's treatment. Although the studies of Baker et al. (1993) and McNown Johnson (1998) offer a broader understanding of families involvement than other, more narrowly defined studies, the data collected was based on staff surveys, not on parents' self-report, indicating a possible discrepancy between staff perceptions of parents' involvement and parents' actual level of involvement in addition to not reflecting the meaning of the involvement to families.

The Families' Perspectives

There is limited research that has considered a wider definition of family involvement from a families' perspective. Baker, Blacher and Pfeiffer (1996) created a study that measured family involvement as frequency of contact with their child, participation in social and educational activities as well as parents' participation in treatment planning. Two-thirds of families were found to have contact at least weekly with their children, mostly through phone calls. Parents also took part in talking with staff members and participating in planning and decision-making about their children's program. Fewer respondents observed the program or participated in groups themselves. The study also demonstrated that although contact between the child and family slightly decreased with longer placements, family involvement in the program did not lessen over time. While this study deepens our understanding of families' frequency and level of involvement at certain agencies, it does not tell how these families experienced this involvement at the agencies.

Kruzich, Jivanjee, Robinson, and Freisen's (2003) study did offer insight into caregivers' experience of their involvement, specifically looking at the caregivers' perception of supports and barriers to their involvement. The researchers measured family involvement as contact between children and their caregivers as well as caregivers' participation in education planning or treatment planning. The families indicated that distance from the facility was the most important barrier and also named family circumstances such as work schedules, transportation issues and child care arrangements as well as facility based barriers, such as communication issues with staff and a lack of encouragement for involvement, as barriers to their involvement. Having an assigned contact person at the facility, timely communication about issues and concerns as well as flexible meeting times and being treated with respect by staff were identified as supports to their participation. The researchers suggest that parents' perception of barriers and support affects their involvement and also highlight that this study does not consider which barriers and supports affect each of the multiple types of family involvement (Kruzich et al, 2003, p. 1517). In other words, although it is clear in general what supports and barriers exist, it is not understood how these impact levels of participation in specific activities.

In an interview by John Powell (2000), Sandra Spencer, a parent of a child in RTC and an advocate for mental health care for children, described her experience as a parent of a child who had been a resident in multiple RTCs. Spencer underscored the importance of how she was treated by staff as a main contributor to her positive or negative experience at the RTCs. She discussed the importance of staff members listening to parents, allowing parents to share their knowledge of the child as well as their

hopes for the child. She felt staff and families needed to show each other "mutual respect" indicating the importance of staff-parent relations in impacting families' experiences at an RTC (Powell, 2000, p. 41).

The families in the study of Kruzich, Friesen, Williams-Murphy and Longley (2002) also highlighted the significance of staff attitudes to their experience. Although the focus of the study was to compare the experiences of African American families with non-African American families at an RTC, both groups of families emphasized the need to be "respected, valued and more involved in making decisions about their child's treatment" (p. 463), even though their experience with decision making "varied widely" among all parents interviewed (p. 463). Families' experiences with staff as well as with treatment planning and decision-making are areas these families have highlighted as important issues to further explore.

Similarly, Demmitt and Joanning (1998) asked families how they experience the residential treatment process for their children, and families indicated a desire to be more involved with making decisions and setting goals about their child. The authors focused many of their questions on family's experience of family therapy, leaving unexplored other aspects of involvement, such as participation in day-to-day activities and treatment planning/implementation, which could offer parents more opportunities for decision making and determining treatment goals.

Instead of having professionals define the benefits of family involvement for parents, De Boer, Cameron and Frensch (2007) allowed families to define what they felt was beneficial and useful to them. In this study, the authors considered parents' perceptions of benefits that residential treatment provided for themselves and the placed

child's siblings and found that parents indicated the importance of respite, feeling welcomed and understood by RTC staff as well as improved personal and family functioning as three benefits of their child being placed in RTC.

Areas for Future Research

Family involvement in RTCs has undergone an evolution over the past fifty years. While originally parents were excluded from their child's treatment, parents have increasingly taken on a greater role in their child's life and treatment at the RTC. Influenced by the focus on family centered care in the mental health field, RTCs have expanded their vision of how to work with parents, viewing them as partners in the treatment of their child, not just as passive recipients of the RTCs expertise.

More research is needed to refine models for best practices for family involvement and create family centered RTCs. The literature on family involvement and family centered residential treatment programs illustrate the multitude of ways that parents can and should be involved at these programs from phone contact and visits to taking part in therapy, training, support groups as well as being involved in the daily activities, treatment planning and decision making for the child. A majority of the research into family involvement, however, has focused on limited aspects of family involvement, such as therapy, training and contact, leaving uninvestigated other key areas, including day-to-day involvement and treatment planning/implementation.

The areas of day-to-day involvement and treatment planning/implementation are particularly important to study since they would likely involve high levels of interaction and negotiation with direct care and clinical staff, which has been highlighted in the literature by staff and families as a possible area of conflict. Furthermore, an

investigation into these two areas of involvement would promote our understanding of how to effectively engage families in collaborative decision making, which the literature indicates has had varied levels of success in RTCs.

By learning from parents and caregivers about their experiences with their child's RTC, this study aims to increase our understanding of current family involvement practices at RTCs as well as to identify possible areas for improvement and future areas of research. The study will focus on two unexamined areas: day-to-day activities and treatment planning/implementation at the RTC and consider multiple aspects of parents' experience in these two areas. How are parents and caregivers involved in the day-to-day activities and treatment planning/implementation for their child? How satisfied are parents with their amount of involvement and decision making opportunities in these two areas? How satisfied are parents with their interactions with direct care staff, therapists and psychiatrists? What do parents and caregivers perceive about the attitudes of staff, therapists and psychiatrists regarding their involvement? Are there relationships between certain demographic variables related to the RTC, child and child's placement and parent satisfaction with their involvement? What barriers and supports affect parent involvement? What impact do parents perceive their involvement has on them, their children and their families? What advice would parents give to other families and RTCs to more effectively work with families?

CHAPTER III

METHODOLOGY

This study was designed to deepen our understanding of parents' and caregivers' experiences in Residential Treatment Centers (RTCs). By directly accessing parent voices, the study examined their participation in two unexplored areas of family involvement at RTCs: day-to-day activities and treatment planning/implementation. The study asked parents to describe their types of involvement in these two areas, their satisfaction with aspects of their involvement as well as certain factors that might influence or affect their level of satisfaction and amount of involvement with their child's day-to-activities and treatment. Finally, the study sought parent feedback on the impact of involvement for families and possible areas of improvement to make RTCs more family centered.

A mixed-method, exploratory survey was created to answer the following questions: 1) how are parents' and caregivers' currently involved in residential treatment centers in the areas of day-to-day activities and treatment of their child and how satisfied are parents with their amount of involvement in these two areas 2) how satisfied are parents with their opportunity for decision making in these two areas 3) how do parents and caregivers describe staff, therapists and psychiatrists' attitudes towards their involvement and how satisfied are parents with their interactions with day-to-day and clinical staff 4) are there relationships between parents' and caregivers' satisfaction with aspects of their involvement and demographic characteristics regarding the RTC, child

and child's placement 5) what barriers and supports affect parents' and caregivers' involvement 6) what impact do parents and caregivers perceive their involvement has for them and their family and 7) what advice would parents and caregivers provide to Residential Treatment Centers and families about family involvement. Although originally qualitative interviews were considered for the study, a mixed-method survey was chosen to capture the diversity in experiences that exist in RTCs and to collect both parents' impressions of their involvement while comparing differences in involvement across different RTCs. The exploratory nature of the study allowed for the possibility of "generating insights" about this "relatively new and unstudied" area of mental health care in order to suggest areas for possible further research (Rubin & Babbie, 2007, p. 29).

Although no official reliability or validity tests were run on the survey instrument, it was reviewed to ensure the language would be appropriate and that directions and questions were clear. The first draft of the survey was distributed to two professionals in the social work field with expertise in working with families and survey design. These professionals reviewed the survey and offered revisions that were included in the final version of the survey.

Sample

Individuals eligible to participate in the study were 1) over 18 2) able to read and write in English and 3) the biological parent, adoptive parent or primary caregiver of a child who was in residential treatment for at least three months sometime between 2005 and the present and whose child was under age 18 at the time of admission. To screen out non-eligible participants, all respondents were asked to confirm they matched the above criteria at the beginning of the survey before continuing the remainder of the survey.

Non-probability, purposive and snowball sampling was used in an effort to obtain a diverse sample of participants that had experiences with a range of RTCs throughout the country and whom the researcher determined could provide the most useful information for the study's research question (Rubin & Babbie, 2007, p. 167). Since there is a high level of variability in the size, programming, philosophies and family involvement practices at residential treatment centers across the country, recruiting from multiple sources would allow for a diverse sample that could capture both the range of experiences as well as any commonalities that might exist between facilities. Since parents' and caregivers' level of participation was likely impacted by their access to resources and it would be important to capture the voices of participants who had fewer resources, thus, a printed version of the survey as well as an online survey were created so access to computers was not an exclusionary factor for the sample.

Thirty-four respondents completed the survey for my study. A total of fifty-two respondents accessed the survey online of which four did not complete the informed consent and fifteen only completed the survey through the demographic questions, leaving the majority of the survey blank. Of the 34 completed surveys, 33 were completed online and one respondent completed and mailed in a printed version of the survey. Seventeen respondents requested and received printed versions, but never sent them in.

Recruitment

Recruitment for the survey was done through helping professionals with direct contacts to families, organizations with memberships that may include families with children in RTCs, and conferences. Recruitment took place from December 2009

through April 2010. My initial recruitment strategy was implemented from December through February. It consisted of 1) emailing my personal contacts and selected mental health advocacy and research organizations that have access to families 2) recruiting at a mental health conference for families and 3) posting at online mental health discussion groups for parents.

To recruit participants for the survey, I primarily used my personal contacts in the social work field and in residential treatment centers in different geographic areas in the country. These contacts were former staff and interns as well as current therapists and directors of family agencies and RTCs in Massachusetts, Vermont, New York, California, Alaska, Texas, Virginia, Washington DC and Maryland. In January, I sent these contacts a recruitment letter (Appendix G) and a recruitment flyer (Appendix F) by email. The recruitment flyer explained my study and included tear-off portions with the website of my survey and my phone number for participants to take with them. The flyer offered participants the choice of 1) going online to www.rtcparents.com (Appendix H), which had a link to the survey (Appendix E) on www.surveymonkey.com or 2) calling me to send them a printed version of the survey (Appendix E) and a stamped/self-addressed envelope.

I asked each of my personal contacts to follow their agencies' policies for recruitment and to 1) distribute the flyer directly to participants who might be interested 2) mail the flyers to families they have worked with and/or 3) post the flyer in an area, such as a waiting room or family therapy room in their workplace, where possible participants would see it. I also asked these contacts to pass the flyer on to any of their contacts who might be able to reach more participants. During this first stage of

recruitment I also completed an IRB application for the Cabinet for Health and Family Services in Kentucky, who distributed my flyer to family agencies throughout the state of Kentucky (Appendix B).

In addition to my own personal contacts, I contacted the American Association of Children's Residential Treatment Centers, the national, state and local branches of the National Federation of Children's Mental Health (NFCMH) and National Association of Mental Illness (NAMI), the Research and Training Center of Family Support and Children's Mental Health in Portland, Oregon and University of South Florida's Research and Training Center for Children's Mental Health to ask them to distribute my flyer and study summary to their mailing lists, members and clients and/or to post the information about my study at their site. In response to a request made by the NFCMH branch in Alaska to add their organization's name and number to my informed consent, I added their contact information as a referral source, and the branch then distributed my survey to their membership.

The National Federation of Children's Mental Health hosted their 20th anniversary annual conference on December 4-6, 2009 in Washington, DC. I had a table during the informational session of the conference and distributed my flyer and hard copies of my survey with stamped/self addressed envelopes to professionals and possible participants.

In addition, I became a member (screen name `lucy_f`) of online discussion groups at www.nami.org and www.healthyplace.com. I entered discussions for parents of children with mental health issues. I introduced myself as a master's student doing a thesis on parent/caregiver's experiences at their children's residential treatment centers and provided the web address of my survey. I attempted to make this posting at

<http://fourms.psychcentral.com>, but was denied access due to the discussion group's rules about protecting its members' privacy. Finally, at the end of all of the surveys (both print and online versions), I asked participants to pass on my survey web address or phone number to other people they thought would be interested in participating.

In the first month of data collection, two respondents did not complete the informed consent of the online survey but went on to complete some of the remainder of the survey. After realizing this issue in mid-January, I changed the settings on my online survey to require respondents to sign the informed consent before continuing the survey. By the end of February, I had 26 respondents. Since my sample size was less than 50, I consulted with my thesis advisor and then launched another recruitment effort in order to reach more possible respondents. I submitted an application to recruit at an RTC in the Boston area but was denied permission since my recruitment would have competed with the agencies' efforts to survey families. I also completed an IRB for Sheppard Pratt Health Systems, and in late March, I received approval to distribute flyers at one of their RTCs in Maryland (Appendix C). I then emailed each of my personal contacts again, reminding them of my study and asking for additional support to contact families. I received emails from several of these contacts stating they would distribute my survey information to their clients. Finally, I reposted my survey link on parent discussion groups at www.nami.org and www.healthyplace.com. I ended my second round of recruitment in mid-April after collecting surveys from 34 respondents.

I was not very successful in my attempt to recruit respondents without computer access. Only two respondents contacted me by phone for a printed version of the survey and of the fifteen surveys I distributed at the National Federation of Children's Mental

Health conference, only one was returned to me. I may have had a better response from conference attendees if I had collected their contact information and followed-up with them after the conference to remind them about the survey and to answer any questions. The University of South Florida was the only agency that did not respond to my request for recruitment. Several local and state agencies for the National Federation of Children's Mental Health notified me that they distributed my flyer through their mailing lists and websites. The Research and Training Center of Family Support and Children's Mental Health posted my survey information in their monthly newsletter which has over 90,000 subscribers. My personal contacts proved to be the most responsive for my recruitment requests, distributing the information at their own agencies and passing the study information on to other contacts.

Ethics and Safeguards

The thesis proposal was submitted and approved by the Human Subjects Review (HSR) board at Smith School for Social Work, to ensure all possible efforts to maintain confidentiality (Appendix A). The HSR further reviewed the proposal to certify that all efforts were taken to consider and minimize the risks of participating in the research.

The informed consent outlined the study, including the potential risks and benefits of participation, the ethical standards and measures to protect confidentiality and the researcher's contact information for questions and comments (Appendix D). All participants agreed to the Informed Consent who are included in the analysis; surveys of participants who didn't complete the informed consent were destroyed. Participation in the study included a risk of having strong feelings about their child or their experience at the residential treatment center. A list of referral sources was added to the informed

consent form on both the online and printed version of the survey. Since the surveys were voluntary, the participant should not have felt obligated or coerced to participate.

Participants may have benefitted from sharing their experiences as well as knowing their voices, experiences and opinions have been heard. They may have also benefitted from knowing that the results of my study will be shared with residential treatment centers in different areas of the country in an effort to improve how residential treatment centers work with families.

The online surveys were anonymous since Survey Monkey does not collect the names or addresses of participants. Participants were reminded in the online informed consent to leave out identifiable information about themselves and their children on the survey and all identifiers, including names, or names of facilities, were removed from the survey. This precaution was also noted in the online consent form. Surveys submitted online were only accessible to the researcher by password. At the close of analysis, all online surveys were downloaded as a file to a portable media device that was stored in compliance with research standards. The survey and all associated files were removed from survey monkey on April 22nd and similarly stored.

The printed surveys were not anonymous, but the following safeguards to ensure confidentiality were taken. Information, including phone numbers and mailing addresses, about participants who called me to request a printed version were not recorded. Participants were reminded in the informed consent to leave out identifiable information about themselves and their children on the survey. All identifiers, including return envelopes, names, or names of facilities, were removed from the survey and this precaution was also noted in the consent form. The return envelopes were separated from

the consent form and survey and destroyed. The mailed consent form was separated from its survey and stored in a secure location.

All materials from the study will be kept secure for three years as required by the Federal government and will be destroyed at that time or kept secure until no longer needed and then destroyed.

Data Collection

Interested participants had access to the online and print version of the survey from December 2009-April 2010. The data for this research study was collected through the use of a mixed method survey that was created by the researcher. A confidential, print version of the survey was created on Microsoft Word. An anonymous, online version of the survey was constructed and managed using the Survey Monkey online program. The questionnaire consisted of four sections with a combination of 27 multiple choice, likert scale and open-ended questions (Appendix E).

The first section of the survey inquired about participant's demographic information including age, income level, ethnicity, relationship status, number of children under care and information about the child's age, length of stay and number of times in RTC as well as the voluntary or mandatory nature of placement. Next, in section A, the survey asked participants about their involvement in day-to-day activities of their child. Participants were asked to list types of involvement and note the frequency of the involvement. Likert scales were used to determine participant's level of satisfaction with the amount of involvement, decision making opportunities and staff interactions during their day-to-day involvement. Each likert scale question also included sections for respondents to explain their responses. The last question of Section A asked respondents

to describe the attitudes of daily care staff toward family involvement. Section B then asked respondents about their involvement in their child's treatment planning/implementation. Respondents selected from a pre-determined list the type and frequency of involvement in their child's treatment. Likert scales were again used to determine participant's level of satisfaction with the amount of involvement, decision making opportunities and interactions with therapists and psychiatrists during their involvement in their child's treatment. Each likert scale question also included sections for respondents to explain their responses and the last question of Section B asked respondents to describe the attitudes of treatment providers toward family involvement. The final section, section C, focused on the respondents' overall experience with their RTC. A likert scale question asked parents to rate the level of emphasis on family involvement at the RTC. This was followed by five open-ended questions that were used to further describe their experience and involvement, including the barriers and supports to their involvement, the impact their involvement had on them and their children as well as advice they would give to RTCs and families. All questions were developed based on themes prevalent in some of the scholarly literature on this topic as well as the researcher's professional experience at a residential treatment center.

Data Analysis

Data collected from the one returned printed version of the survey was entered manually into Survey Monkey by the researcher and added to the data collected from the online surveys. In some instances, respondents did not answer all questions; as long as respondents answered the majority of questions (excluding demographics) they were included in analysis. All data was cleaned before the start of analysis. Multi-step

questions were checked for accuracy and adjusted as needed. All identifiable information such as names of children, geographical names and facilities was deleted from the open-ended responses. This data was also read by the researcher to ensure comprehensibility with any illegible entries deleted. Analysis of the mixed-method survey consisted of three parts: descriptive statistics for all demographic, checklist and likert scale questions, qualitative analysis of open ended responses, and inferential statistics that looked at relationships between demographic characteristics and likert responses. Details of these analyses are provided below.

Descriptive statistics were used to describe the sample population demographically and to provide summary information for survey responses. The results of the surveys were exported to Microsoft Excel and using Excel's statistical tools, frequencies were run for the following demographics: respondent status as a parent or caregiver, respondents' age, ethnicity, marital status, income level and number of children under their care, child's age at time of placement, number of times in placement, length of stay in the RTC and nature of placement (mandatory versus voluntary) and respondents' assessment of the level of emphasis on family involvement at the RTC. For the six likert scale questions asking satisfaction with amount of involvement, decision making and staff interactions, the responses were divided into three categories: very satisfied/satisfied, very dissatisfied/dissatisfied and neutral. For each question, the frequency and percentages of each category were calculated.

Thematic analysis was used on the open-ended questions. Responses to each open-ended question from both the online and print versions of the survey were manually entered by the researcher into separate text tables. The researcher read through the first

response, noting possible themes/categories. Then using the "method of constant comparison" (Anastas, 1999, p. 424), the researcher continued on to the additional responses in order, adding or revising themes based on the previous responses. The resulting tables for each open-ended question were grouped according to these themes/categories. The majority of these responses included 1-2 themes although a few responses had 3 or 4 themes. In addition, the responses that included open-ended explanations to the likert scale questions were grouped by the following categories: very satisfied/satisfied, very dissatisfied/dissatisfied and neutral, and then coded for notable patterns.

For the question in section A that asked respondents to list types of involvement in the day-to-day activities in the RTC, the researcher grouped similar responses for types of involvement and calculated and ranked the frequency of each type of involvement among all respondents. The responses were also ranked by frequency of occurrence, either daily, weekly, monthly, or 1-2 times. These responses were then compared with respondents' level of satisfaction with their involvement to note patterns between number of types of involvement and level of satisfaction. For the question in Section B asking treatment involvement and frequencies, the researcher separated the types of involvement into two groups: those that never occurred and those that did occur. Of those that did occur, the types of involvement were ranked by overall frequency as well as frequency by each time option (daily, weekly, monthly, 1-2 times).

Inferential statistics were used to compare two subgroups to each other. Differences based on child's age, child's length of stay, number of times child was in an RTC placement as well as the nature of placement in residential care (mandatory v.

voluntary) and participants' assessment of the RTCs emphasis on family involvement were examined with respect to the following survey responses: satisfaction with amount of involvement, satisfaction with decision making opportunities, and satisfaction with interactions with staff, therapists and psychiatrists in day-to-day activities and treatment planning/implementation. Both t-tests and chi square tests were used to examine these relationships. Marjorie Postal, Smith's statistical consultant, provided the analysis support for these statistics.

CHAPTER IV

FINDINGS

This study investigated parents' and caregivers' experiences with their child's residential treatment center by examining their involvement in their child's day-to-day activities and treatment planning/implementation. Participants completed a survey (Appendix E) that asked the following questions: How are parents and caregivers involved in the day-to-day activities and treatment planning/implementation for their child? How satisfied are parents with their amount of involvement and decision making opportunities in these two areas? How satisfied are parents with their interactions with direct care staff, therapists and psychiatrists? How would parents and caregivers describe the attitudes of staff, therapists and psychiatrists regarding their involvement? What barriers and supports affect parent involvement? What impact do parents perceive their involvement has on them, their children and their families? What advice would parents give to other families and RTCs about family involvement?

This chapter will present the major findings from this study beginning with the demographics of the sample. The chapter will then describe respondents' involvement in their child's day-to-day activities and treatment and their satisfaction with their amount of involvement in these two areas. This will be followed by parents' and caregivers' satisfaction with decision making opportunities in these two areas, their satisfaction with their interactions with staff, therapists and psychiatrists, and their perceptions regarding staff and treatment providers' attitudes towards their involvement. Next, the chapter will

discuss relationships between respondents' satisfaction with certain aspects of their involvement and demographic characteristics related to the RTC, their child, and their child's placement. The chapter will then provide a description of the barriers and supports to their involvement as well as the impact their involvement had on them, their children and their families. The chapter will end with parents' and caregivers' advice to other families about RTCs and to RTCs on how to more effectively work with families.

Demographics

The data from thirty-four respondents was used for this study. Although a total of forty nine-respondents consented to my survey, fifteen of these respondents were excluded from the study because they filled out less than 50% of the survey, not answering any of the questions in section A through C.

Of the 34 respondents, 91% were parents of children in RTCs while 9% were primary caregivers. The sample of respondents was diverse in age and economic status but not in ethnicity. 91% of the respondents identified themselves as white, 6% were black, and 3% (n=1) identified as other, "Peach American." The ages of the respondents showed a more even distribution with 32% being 30-40 years old, 30% being 40-50 years old and 38% being 50-60 years old. The economic status of the respondents also showed a wide range. The breakdown of respondents' annual household income is as follows: 38% of the respondents reported \$40,000 or less, 36% reported \$40,000-80,000 while 26% reported \$80,000 or more.

The respondents also had varied family make-ups. The majority of respondents were married, making up 65% of respondents, while 8% were divorced, 12% had live-in partners, and 15% were single. Most of the respondents, or 62%, had more than one

child under their care with 35% having 2 children, 15% having 3 children, 9% having 4 children, and 3%, or 1 respondent, with six or more children. Thirty-eight percent of respondents had only one child under their care. The demographic characteristics of the respondents are illustrated in Table 1 below.

Table 1

Demographic Characteristics of the Respondents

n=34	Parents	91% (31)
	Caregivers	9% (3)
Age	30-40	32% (11)
	40-50	30% (10)
	50-60	38% (13)
Ethnicity	White	91% (31)
	Black	6% (2)
	Other (Peach American)	3% (1)
Annual Household Income	Less than 25,000	18% (6)
	25-40,000	20% (7)
	40-60,000	18% (6)
	60-80,000	18% (6)
	80-100,000	8% (3)
	Above 100,000	18% (6)
Relationship Status	Single	15% (5)
	Married	65% (22)
	Divorced	8% (3)
	Live-in Partner	12% (4)
Children under Care	1	38% (13)
	2	35% (12)
	3	15% (5)
	4	9% (3)
	5	-----
	6 or more	3% (1)

The sample was also diverse regarding the age, reason and length of stay of their child in treatment at an RTC. Fifteen percent of the children were age 10 and under, 44% were ages 11-13 and 41% were 14 and over. A large majority, or 74%, of the children were voluntarily placed while 26% were mandatory placements. The length of placements for children ranged from 1 month to 66 months. Twenty-four percent of the children were in RTC for 6 months or less, 42% of children were placed between 7 and 12 months and 35% were in RTCs for over 12 months. For 20, or 59% of the respondents, their child had been placed one time in an RTC while 14, or 41%, had been in multiple placements. Of the 14 children who had been in multiple placement, 29% had been in twice, 43% had been in three times, 14% had been in 4 times and 14% had been in 5 or more times. Table 2 illustrates the demographic characteristics of the respondents' children.

Table 2

Demographic Characteristics of the Respondents' Children

Reason for Placement		
	Mandatory	26% (9)
	Voluntary	74% (25)
Age of Child at time of Placement		
	10 years and under	15% (5)
	11-13 years	44% (15)
	14 years and over	41% (14)
Length of Placement		
	6 months and under	24% (8)
	7-12 months	41% (14)
	Over 12 months	35% (12)

Number of Placements		
	1	59% (20)
	2	12% (4)
	3	17% (6)
	4	6% (2)
	5 or more	6% (2)

RTCs and Family Involvement

The large majority of respondents indicated that their child's RTC emphasized family involvement. Of the 33 respondents that answered this question, 34% reported a strong emphasis, 38% reported some emphasis, 25% reported minimal emphasis and 3% (n=1) said there was no emphasis placed on family involvement at their RTC.

Respondents also indicated a range of types of participation in their child's day-to-day activities and treatment.

Day-to-Day Involvement

Respondents were asked to identify both the types and frequency of involvement they had in their child's day-to-day activities. Sixty-eight percent of respondents identified having some type of involvement in their child's day-to-day activities, 12% said they had no involvement in day-to-day activities and 20% left this question blank. Two respondents indicated they had no involvement because the RTC "did not want us" and the RTC "was too far from home."

Table 3 illustrates the types and frequency of involvement in day-to-day activities indicated by the respondents. The most popular type of involvement was attending special celebrations/holidays, followed by eating snacks/meals with their child, taking part in sports/activities/outings, having visits and phone calls, providing educational support and helping with hygiene/doing their child's hair. Respondents also indicated

they took part in buying/supplying clothes, communicating with staff, bringing their children to doctor's appointments, putting their children to sleep and attending a parent education group.

Table 3

Participation in Day-to-Day Activities

Type of Involvement	Total Respondents Involved (Greatest to Least)	Daily	Weekly	Monthly	1-2 times
None*	33.3% (11)				
Special celebrations/holidays	29.4% (10)			3	7
Snacks/meals	26.5% (9)		7		
Sports/outings/activities	25%(8)		3	2	1
Visits	20.6%(7)		5		
Phone calls	20.6% (7)	6			
Educational support (reading, visiting school, homework monitoring)	15.2% (5)		3	1	
Hygiene/doing child's hair	15.2% (5)		2	1	1
Buying/supplying clothes	11.8% (4)		1	1	2
Communicating with staff	5.9% (2)		1		
Bringing to doctor appointments	5.9% (2)			1	1
Putting child to sleep	2.9% (1)		1		
Parent education group	2.9% (1)			1	
*includes blank responses and "none" responses					

Making phone calls was the only activity done daily by respondents. Having snacks/meals with their children was the most common weekly activity followed by weekly visits. Attending special celebrations/holidays was the most common monthly activity as well as the most common activity that occurred one-two times during their child's stay.

Satisfaction with Day-to-Day Involvement

Respondents were asked to rate their level of satisfaction with their amount of involvement with their child's day-to-day care. Twenty-nine respondents answered this question. Of those, 45% were satisfied or very satisfied with their level of involvement in the day-to-day activities at the RTC, 34% were unsatisfied or very unsatisfied and 21% were neutral. Respondents who were unsatisfied/very unsatisfied described a range of issues including the distance of the facility from their home and specific RTC policies, such as inconvenient visiting hours, which inhibited their involvement. Several respondents described never being asked, "invited" or encouraged to be involved. One parent felt their involvement was "treated more as an intrusion and annoyance" despite being "encouraged within parent handbooks" at the RTC. On the other hand, the satisfied/very satisfied respondents described RTCs that "encouraged" their involvement, kept them informed and allowed parents to "choose" the amount and type of involvement they wanted in their child's day-to-day activities.

The number of types of involvement seems related to the respondents' level of satisfaction with their involvement. Of the 13 respondents who stated they were satisfied or very satisfied with their level of involvement, 46% of them listed 3-7 types of involvement and 46% had 1-2 types of involvement while only one parent who was

satisfied listed no types of involvement. Of the 9 respondents who were unsatisfied or very unsatisfied with their amount of involvement, 56% were not involved at all while 33% had only type of involvement listed. Of the 13 satisfied/very satisfied respondents, 30% had daily contact by phone while 46% had weekly visits and meals. Sixty-nine percent of satisfied/very satisfied parents participated in special celebrations monthly or 1-2 times during their child's treatment. This finding suggests a relationship between satisfaction with involvement and level of involvement.

Involvement in Treatment

Respondents had a range of participation in their child's treatment planning and implementation as illustrated in Table 4 below. Overall the most popular forms of treatment participation that occurred at any frequency (either daily, weekly, monthly or 1-2 times) were phone contact with the therapist and meeting the therapist, both of which were done by 97% of respondents. The next most popular form of participation was family therapy done by 88% of respondents, followed by participating in treatment meetings (85%), making treatment goals (82%), revising goals (74%), phone contact with the psychiatrist (74%) and meeting the psychiatrist (71%). Nearly a third of participants hadn't met or talked with the psychiatrists at all during their child's most recent placement.

Weekly phone contact with the therapist was the most popular form of treatment participation, followed by weekly family therapy, meeting the therapist weekly, attending monthly treatment meetings, participating in making treatment goals 1-2 times, and meeting the psychiatrist 1-2 times. Monthly phone contact with the psychiatrist, making treatment goals monthly, revising treatment goals 1-2 times, meeting the therapist

monthly, phoning the psychiatrist 1-2 times and monthly family therapy were the least frequently completed treatment activities.

Phone contact with the therapist was the only type of treatment involvement that was done on a daily basis with four participants noting this frequency of involvement. Phone contact and meeting with the therapist most often occurred on a weekly basis while phone contact with the psychiatrist most often occurred monthly and meeting the psychiatrist most often occurred 1-2 times. Study participants most often participated in treatment meetings on a monthly basis, making treatment goals 1-2 times monthly and revising goals monthly. Family therapy participation most often occurred on a weekly basis.

Table 4

Participation in Treatment

Type of Involvement	Daily	Weekly	Monthly	1-2 times	Never
Phone Contact with Therapist	11.8% (4)	64.7% (22)	11.8% (4)	8.8% (3)	2.9% (1)
Phone Contact with Psychiatrist	0.0% (0)	11.8% (4)	35.3% (12)	26.5% (9)	26.5% (9)
Met with Therapist	0.0% (0)	50.0% (17)	29.4% (10)	17.6% (6)	2.9% (1)
Met with Psychiatrist	0.0% (0)	2.9% (1)	29.4% (10)	38.2% (13)	29.4% (10)

Type of Involvement	Daily	Weekly	Monthly	1-2 times	Never
Attended Treatment Meetings	0.0% (0)	9.1% (3)	42.4% (14)	33.3% (11)	15.2% (5)
Participated in Making Treatment Goals	0.0% (0)	14.7% (5)	29.4% (10)	41.2% (14)	14.7% (5)
Participated in Revising Treatment Goals	0.0% (0)	11.8% (4)	35.3% (12)	26.5% (9)	26.5% (9)
Attended Family Therapy	0.0% (0)	58.8% (20)	23.5% (8)	5.9% (2)	11.8% (4)

In addition to the types of treatment involvement listed on the survey, one respondent noted that they also maintained contact with their therapist via email and 2 respondents attended their child's treatment meetings that occurred once every 3 months. Respondents also noted additional types of involvement, one indicating they had "home visits with staff" and one stating they participated in their child's educational meetings. Some respondents further explained reasons for their limited level of involvement. One stated: "since RTC placement, my involvement has been almost zero from the weekly involvement I had while child was in day treatment." Another explained that they did not participate in family therapy "because their son [turned 18] and did not want it" and that they did not participate in treatment because "[they] were not asked to attend any treatment meetings. [They] were not asked to participate in any goals." Other respondents explained issues they had with meeting treatment staff. One stated that they "never met with anyone but [the] therapist" while another shared the following:

I was only able to have phone contact with the psychiatrist on one occasion. They wanted to introduce a medication that had failed in the past and only when the nurse was unable to answer my questions and I insisted that the psychiatrist phone me did I receive a call. I never met him and when I requested to attend treatment team meetings I was denied access.

Satisfaction with Treatment Involvement

Respondents were asked to rate their level of satisfaction with their amount of involvement in their child's treatment planning and implementation. Thirty-three respondents answered this question. Of those answering, 40% were satisfied/very satisfied, 36% were unsatisfied/very unsatisfied and 24% were neutral. Respondents who were satisfied/very satisfied stressed the importance of communication with the treatment team, one stating they felt "kept in the loop" while another explained they had "the ability to pick up the phone and call staff" and "more importantly their son" could call them. Other satisfied respondents highlighted the power of positive relationships with treatment providers. For example, one respondent noted the work of the "very experienced... director and therapist" while another expressed gratitude for working with "the same clinician over period of three years" who "aggressively work[ed] to learn about his disability and how she could effect long term change in his life." Another respondent described meeting with the Program Director "several times a week" who "answer[ed] my questions and explain[ed] to me in a manner that I would understand. She worked with me and treated me with respect and kindness." Two respondents who were very satisfied with their involvement described having high levels of involvement and one explained that her involvement allowed her "to learn a lot from the staff."

Respondents who were unsatisfied with their involvement reported a range of issues. Issues included: distance of facility from home, children not wanting their

involvement in treatment, and children adopting racist behaviors during their stay. One respondent discussed an issue with an outside personnel, a CASA staff, that prevented her involvement in the treatment of her child. Others highlighted specific issues with the RTC and staff. Several respondents expressed dissatisfaction with their limited or non-existent involvement in treatment. One respondent stated that the implementation of her suggestions "happen[ed] so slowly" while others stated they had to "insist" and "fight" against staff "roadblocks" to be involved and have their suggestions considered. One respondent stated that she needed more "instruction and support" to have the "tools to be more involved in treatment planning" while another parent highlighted the importance of "the family trust[ing] every member of the team." One respondent stated that she was dissatisfied that treatment goals were not individualized for each child and that every child received the same goals. Two respondents stated that their RTC would say they want involvement and complain when there is none but did little to encourage or nurture that involvement. For example, one respondent stated:

In any other medical environment, parent's questions about their child's illness, treatment modalities, medications, and aftercare would be pertinent, encouraged, understood, and addressed. In the mental health care field, parents that request information are viewed as troublemakers although those same parents will be expected to care for their child upon their return home. While most professionals in this field complain about a lack of family involvement amongst families, and admissions material touts the importance of such involvement, in reality, it is not strongly encouraged and parents have little access to the treating psychiatrist who generally only sees the child once per month for a matter of ten to fifteen minutes.

Decision Making

In Day-to-Day Activities

Respondents were asked to rate their level of satisfaction with their opportunity to make decisions about their child's day-to-day care. Thirty-three respondents answered

this question. Of those who answered, 43% indicated being satisfied/very satisfied, 39% were unsatisfied/very unsatisfied and 18% were neutral. Those who were unsatisfied, very unsatisfied and neutral regarding decision making highlighted multiple issues, both external to the RTC and within the RTC itself. For example, one parent explained that they had to "relinquish custody for mental healthcare to DCFS" because they could not afford his treatment. They expressed the pain this caused them: "We want to be involved in his life very much. It is hurtful not to be able to make normal parenting decisions for our son." Another parent highlighted the issue of distance as a reason for their inability to be involved in decision making on a day-to-day basis because of their distance from the facility.

Parents who were neutral or dissatisfied shared similar concerns, indicating that they had disagreements with how staff cared for their children. These respondents felt they had "no input opportunities" or were unsure whether their input was addressed. Parents who were unsatisfied with their decision making described RTCs that "never asked" or permitted them "no say" in their child's day-to-day care. Other parents described RTCs that involved them but then were "told we were wrong" or were "told late" after changes were already made. In contrast, parents who were satisfied felt they were either "well informed" of "how and what [their child] did each day" or "always contacted" when there were issues and before changes were made. Satisfied parents felt that their "requests and concerns were always addressed and incorporated into our child's plan." One satisfied parent explained that even though "I am not directly involved with the day-to-day care, I do know what is happening and can make suggestions as necessary. I have found the staff generally implement my suggestions."

In Treatment

Respondents were asked to rate their level of satisfaction with their opportunity to make decisions about their child's treatment. All 34 respondents answered this question with 47% being satisfied/very satisfied, 41% being unsatisfied/very unsatisfied and 12% being neutral. Several respondents who were unsatisfied explained they had issues with their access to and interaction with the treatment team. One parent disagreed about medication used for their child while another parent explained it was difficult to obtain information directly from the psychiatrist in charge of their child's care. Some respondents related their dissatisfaction to staff who seemed disinterested in their involvement. One parent discussed having to "insist" or "push the issue" to be a part of the treatment team. Another parent stated that even when they felt they "had access to treatment meetings" they still felt "out of the loop" because they did not have the mental health training to have "access to how decisions are made." Others highlighted RTC policies that led to their dissatisfaction. For example, one parent described an RTC policy that psychiatrists do not return phone calls, are not available for phone consultations and can only be talked to in person at treatment meetings, which were held during the weekday. Finally, these respondents highlighted issues with the legal and court system, which mandated treatment they believed unnecessary and ineffective or ended treatment prematurely.

A dissatisfied parent explained the benefits and necessity of involving families in treatment decisions: "Families have lived with their loved ones with mental illness and endured many trials and tribulations before residential care is sought. These family members need to be involved in formulating treatment plans [and] in sharing information

about their child's symptoms and behaviors." Another parent reiterated these sentiments, "The caseworker...the therapist...don't know our son well-enough to know what is best, yet are making all the decisions. The best treatment plans are family driven and now we know why. Too many unknowing people make things worse."

Parents who were satisfied with their decision making regarding their child's treatment shared examples of treatment staff and parents working together to benefit the child. Parents described staff who were willing to "hear their suggestions and concerns" and "implement them when appropriate" while parents were willing to "try" the suggestions of psychiatrists and therapists even when they were not "sure" about them. Parents felt they were treated with "respect" by a "responsive" staff who kept them "informed" and allowed them to give "input." Several parents indicated the importance of planning for discharge in treatment plans with one expressing satisfaction with the treatment team's efforts to create goals that could allow their child to be successful at the RTC and at home.

Staff Interactions

Daily Care Staff

A majority of the respondents indicated being satisfied with their interactions with day-to-day staff at the RTC. Of the 32 respondents who answered the question, 66% of respondents stated they were satisfied or very satisfied while only 12% said they were unsatisfied or very unsatisfied and 22% indicated being neutral. Respondents who were satisfied described staff as "accommodating and encouraging" of involvement "welcoming and supportive" before, during and after visits and "open" to "ideas, suggestions and thoughts about daily care." Another parent described staff who were

"receptive to questions," "open to discuss child's challenges" as well as "available to meet" and "open to share daily paperwork" on her child. The parent went on: "They were courteous, polite [and] always had a positive attitude. To tell you the truth, I don't know how they do it everyday. My hat is off to them." Other parents described having positive relationships with staff that grew over time. A parent demonstrated staff responsiveness and support with the following example:

The [staff] knew that I was upset that I couldn't be there when [my son] woke up. But I would tell them to tell him that his Mommy said that she loved him and misses him very much.

Dissatisfied and neutral respondents had a much different experience with the staff. They described staff as "not welcoming" and "not prioritizing contact with us." One parent explained "They just put us in a room to visit while we ate the meal." This stands in contrast to visits held by a satisfied parent who described staff who welcomed their visits and actively supported the child to transition back to the RTC after a visit.

Dissatisfied respondents had a range of experiences with staff. One described well meaning staff who were not "sophisticated enough" to be able to help their child while another stated that staff were "not forthcoming with information [because] the questions were viewed as annoying" or were "condescending as if what we knew about our child was wrong."

Treatment Providers

Respondents were asked to rate their level of satisfaction with their child's therapists and psychiatrists respectively. Thirty-three respondents rated their level of satisfaction with their child's therapist. Of those who responded, 58% were satisfied/very satisfied, 24% were unsatisfied/very unsatisfied and 18% were neutral. Of the 24% who

were unsatisfied/very unsatisfied, only one respondent was very unsatisfied. All 34 of the respondents rated their level of satisfaction with the psychiatrist with 35% being satisfied/very satisfied, 44% being unsatisfied/very unsatisfied and 21% being neutral. Ten of the respondents, or 29%, were very unsatisfied with their psychiatrist. Overall, respondents expressed higher satisfaction with therapists than psychiatrists.

The respondents' narratives regarding their interactions with their child's therapist and psychiatrist matched these satisfaction results with more people expressing positive experiences with their therapist and negative experiences with their psychiatrist. For some respondents this was based on the lack of interaction with the psychiatrist compared with the therapist but for many it was a difference in their attitudes towards parents. These respondents described psychiatrists who were difficult to reach, hard to understand, and seemed "threatened" by [parents'] input and questions. One respondent described the psychiatrist as having a "heart of ice." On the other hand, these respondents had positive experiences with their child's therapists whom they described as "easy to reach," "wonderful," "extremely understanding" and "supportive" and who were "interested in [parent] opinions," "welcomed [parent] input" and "worked hard to negotiate when disagreements occurred." Some respondents, although they had more positive interactions with their therapist than the psychiatrist were still more neutral regarding their experience with their therapist. These respondents shared concerns that therapists were welcoming as long as there were no disagreements or the right questions were asked. One respondent explained that although the therapist was supportive they were not able to "provide concrete answers to questions." There were also a few outliers who did have more positive interactions with psychiatrists than with their therapist who

were unwelcoming and psychiatrists who were more open to the respondents' thoughts and observations.

A few respondents expressed dissatisfaction and did not differentiate between the therapist and the psychiatrist stating that they felt like an "afterthought" and complained about the treatment providers' lack of accessibility and face-to-face meetings. Respondents stated dissatisfaction with being left uninformed about changes in their child's treatment and having their "recommendations always rejected." Some parents described treatment providers who "acted like anything [they] said was wrong" or who "want to do things [their] way, when I know my son better than they do." Another parent felt the providers were "interested only about how my child responded in treatment and not how he was before or planning realistically about coming home." Another said they "didn't really want to hear what I had to say since my husband and I don't have degrees in social work or psychiatry." Overall, these respondents reiterated how individualized and varied their experience was with each treatment provider, regardless of their degree or position, making it difficult to generalize or compare their experiences. In addition, some respondents highlighted the challenge with accurately evaluating the treatment providers, since many of them had changed during their child's time in an RTC and they had a different experience and relationship with each one.

Those respondents who were satisfied with their therapist and psychiatrist interactions described treatment providers with much more positive attitudes towards them and their involvement. These respondents felt that they were "respected" and "welcomed" by therapists and psychiatrists who "wanted [them] involved." Parents appreciated having frequent communication by phone, email and in person as well as

being "kept informed" and notified of changes in the child's condition or treatment. The significant contributions made possible by supportive therapists were met with gratitude as illustrated by the following respondent:

I love our therapist. Our family really went through a lot with our son prior to having him admitted to treatment. We were all broken. And our therapist put us back together. We really do owe her a lot. More than I can say.

Satisfaction Levels Related to Demographic Characteristics

Statistical tests were run to explore the relationship between respondents' level of satisfaction in aspects of their involvement at the RTC and certain demographic characteristics related to the RTC, their child, and child's placement. The mean score was calculated for each of the seven following satisfaction questions: satisfaction with amount of involvement in day-to-day care, satisfaction with decision making opportunities in day-to-day care, satisfaction with interactions with direct care staff regarding day-to-day care, satisfaction with amount of involvement in treatment planning/implementation, satisfaction with decision making opportunities in treatment planning/implementation, satisfaction with interactions with therapists regarding treatment and satisfaction with interactions with psychiatrists regarding treatment. T-tests were then run to examine differences in these satisfaction levels for the following groups: respondents who identified their RTC as having no/minimal emphasis on family involvement and respondents who identified their RTC as having some/strong emphasis on family involvement; respondents whose children were mandatory placements and respondents whose children were voluntary placements; respondents with children who were placed once in an RTC and respondents with children who were placed multiple times; respondents with children who were placed 1-2 times and respondents with children who

were placed 3 times or more; respondents whose children were placed for 6 months or less and respondents whose children were placed over 6 months; respondents whose children were placed 12 months or less and respondents whose children were placed over 12 months; respondents whose children were aged 7-13 at time of placement and respondents whose children were aged 14 and over at time of placement.

Of the 49 t-tests run, only four showed significant differences and are explained below. There was a significant difference ($t(25)=3.287, p=.003$, two-tailed) in satisfaction with amount of involvement in day-to-day care for respondents who identified their RTC as having no/minimal emphasis on family involvement and those who identified their RTC as having some/strong emphasis on family involvement. Those who said the RTC placed some or strong emphasis on family involvement had a higher mean response ($m=3.5$) than those who said it placed none or minimal emphasis ($m=2.0$) suggesting greater satisfaction in day-to-day care when programs were perceived to place greater emphasis on family involvement.

A significant difference ($t(31)=2.590, p=.015$, two tailed) was found in respondent level of satisfaction with their interactions with the therapist for those whose child was placed one time in an RTC ($m=3.95$) than for those whose child was placed multiple times ($m=2.93$) suggesting higher level of satisfaction with their therapist their first time in an RTC. A significant difference was also found in respondents' satisfaction with their amount of involvement in treatment planning/implementation ($t(31)=2.331, p=.026$, two-tailed) for those whose children were mandatory placements and those whose children were voluntary placements. The mandatory group expressed less satisfaction ($m=2.33$) than the voluntary group ($m=3.42$) suggesting that the mandatory

nature of placement impacts parents' satisfaction with their involvement in their child's treatment. Finally, a significant difference was found in respondents' satisfaction with opportunities to make decisions about child's treatment ($t(32)=3.177, p=.033$, two tailed) for respondents whose children were placed 12 months or less and respondents whose children were placed over 12 months. The group with children in placement for 12 months or less was less satisfied ($m=2.68$) than the over 12 month group ($m=4.00$) indicating that parents and caregivers are more satisfied with decision making in treatment in longer placements.

Cross-tab analyses were also used to explore relationships between respondents' level of satisfaction in their involvement and the demographic groups described above. In order to run the test, for each of the seven satisfaction questions, results were grouped by very unsatisfied/unsatisfied and very satisfied/satisfied with all neutral responses excluded. Of the 49 tests run, only five of the cross tabs analyses had large enough cell sizes to run a chi-square test. Of these five chi-square tests, only one demonstrated a statistical difference with respondent level of satisfaction with their opportunity to make decisions about their child's day-to-day care ($\chi^2(1, N=30)=3.999, p=.046$, continuity corrected). A larger percent of the families whose children had been in RTC for 12 months or less were unsatisfied (63.2%) with their opportunity to make decisions about their child's day-to-day care compared to those whose children had been in more than 12 months (18.2%). Overall these statistical tests indicate that parents and caregivers with children that have voluntary, longer-term placements within one RTC that emphasizes family involvement are more likely to be satisfied with various aspects of their involvement.

Barriers

Respondents were asked what barriers, if any, affected their participation in day-to-day activities and treatment planning/implementation. Twenty-nine respondents listed some type of barrier. A thematic analysis was done on these responses and three types of barriers were identified: external, personal and RTC-related.

External Barriers

Eighteen respondents highlighted a number of external barriers that impacted the level of their involvement at their child's RTC. The most common barrier was the distance of the facility from their home, which was mentioned by 15 respondents, or nearly half the sample. Many respondents lived an hour from the facility and one lived 1,000 miles away. Other external barriers included HIPAA regulations that prevented involvement and insurance or court mandates that regulated how parents could be involved.

Personal Barriers

In addition to the external, logistical challenges, eight respondents also described personal barriers that made scheduling involvement even more difficult. Parents mentioned how their work and school, caring for their other children at home, being a single mother, finding transportation to the facility and managing the cost of transportation further limited their involvement.

RTC Barriers

Fifteen respondents noted aspects of the RTC itself that inhibited their involvement. Seven respondents described specific issues with staff who either did not encourage their involvement or actively discouraged their involvement. Respondents

spoke about staff who did not understand the severity of the child's behavior at home or who "were not always ready to accept what parents have to say." One parent said that not having a "skilled family therapy leader" on staff prevented involvement while another mentioned the lack of accessibility of the psychiatrist.

Nine parents noted barriers caused by RTC policies. Some noted a lack of agency policies related to family involvement, seeing no opportunities and feeling no encouragement to participate. One parent noted: "We never see other parents there to do any parent groups or have interaction with them. We don't feel family support." Other respondents noted that even when agencies did have some family involvement, the policies were ineffective or led to them feel unwelcomed. One parent noted that they were asked to participate in treatment meetings "but they wanted us to be involved so they could tell us everything we had every done wrong and they could list all the things that they found wrong with our child." Another described an issue with accessing the psychiatrist for treatment questions and consultations stating that it was the RTC policy that psychiatrists did not have to return phone calls. They noted "HUGE obstacles" in their involvement in treatment planning:

Our ideas were passed along, but we were not actually invited to Monday team meetings until we pushed the issue. We requested to speak w/ the doctor & were told he didn't return phone calls because he had a hectic schedule. We were told there was nothing in the facility rules stating doctors were obligated to do so. The only access we had was on Monday during treatment planning. Even on Mondays, phone consultations w/ the team were not allowed. Attend in person or be excluded.

Other parents shared how restrictive policies, such as limited visiting days and hours and rules regarding outings after a certain time in treatment, as barriers to their involvement.

Parents also noted "a lack of organization" at the facility with "no three way calling:

making it impossible for both parents to participate via phone in the treatment meetings if they were in different locations.

Overcoming Barriers

Despite many of these barriers, five respondents described how parents and RTC facilities had found ways to still keep parents involved. For example, one parent said they "strive not to let [the distance] stop us" with one respondent who even "moved closer to the facility" so that distance would not be an issue. Other respondents described RTCs that were flexible and cooperative especially regarding scheduling and coordinating appointments, therapy and meetings at the caregivers' convenience. One respondent stated that despite the distance she lived from the facility and her scheduling difficulties with work, "the RTC was always willing to work together to meet at mutually convenient times" in contrast to another respondent who had similar constraints but there was "NO request or offer made" to ease scheduling conflicts.

Supports

Respondents were asked to give examples of what supported their involvement in day-to-day activities and treatment planning/implementation. Twenty-six respondents answered the question and noted a range of personal and RTC-related supports that facilitated their involvement.

Personal

Six respondents identified their personal, external support systems as facilitating their involvement. These support systems included understanding workplaces, church and supportive friends and family. Two respondents also noted supportive outside agencies,

such as DSS. One parent expressed gratitude for a social worker who gave gift cards to "pay for all our gas."

Nine respondents noted the support provided by their own personal strength to persevere, which they described as "drive" and "determination to do what is best for my child." Parents noted their "love for their child" as well as their interest in their child's improvement that motivated their involvement. For example, one parent stated:

After years of dealing with my daughter's mental health problems, I have learned that I must advocate for her and advocate for involvement in her care. My strong personality and strength as well as my love and compassion for my child and desire for her to receive the best possible treatment encouraged my involvement. I was able to use their policies which stated they encouraged family involvement as a segue to asking questions and actively participating.

One respondent indicated that it was her "personal desire" which helped her be "proactive" in her involvement which would not have been encouraged by the agency. Another found it was their interest for involvement combined with staff, working in a "team approach," that supported their involvement.

RTC Policies

Many respondents stated specific ways that RTC staff and policies were able to support their involvement. Five parents indicated the support provided by staff from line staff to therapists to directors who were encouraging, provided updates and were supportive to them and their child. One parent felt "reassured" knowing there were staff caring for her child who "became an extension of their family." Some indicated that they felt supported by knowing their child would be safe, would benefit and had the support of professionals "to help us raise her appropriately during that difficult time in our child's life."

Thirteen respondents identified RTC policies and practices that supported their involvement. Respondents noted the support provided by policies that made communication and participation convenient. They highlighted several policies that currently supported them and that they would like to see more of, including holding open houses, allowing daily phone calls, making family therapy convenient by being in person or over the phone, and having frequent visiting hours during the week and weekend. One appreciated support with transportation, including rides and funds for airfare and hotels. Others mentioned the option to have off grounds passes on special occasions and home visits.

Impact of Involvement

Respondents were asked how their involvement impacted them, their family, their child and their child's treatment. Twenty-eight respondents answered this question. Fourteen expressed negativity with their RTC experience and involvement, four expressed a mixed negative and positive experience and ten expressed a positive experience. After thematic analysis was run on these responses, two main themes emerged: the challenges created by their involvement and the positive outcomes due to their involvement.

Challenges

Fourteen respondents, or half of the respondents who answered the question, emphasized how difficult their experience was with their child's placement in an RTC. Of these 14 negative responses, eight expressed very strong reactions to their experience with their RTC describing this time in their life as a "tremendous hardship," "trying," "stressful," "heart wrenching" and "awful" for them. The reasons parents noted for these

challenges were widely varied. Some stated their involvement was often what was difficult for them. In addition to being emotional for parents to visit and then leave their child, it was also a logistical strain as respondents struggled with the burden of balancing involvement in their child's treatment with their other responsibilities of work, school and childcare. Logistical issues, including the distance and time to travel to the RTC, further compounded these challenges. One respondent described feeling "pulled away" from her work and the "rest of her family" while another respondent felt like "a bad mother" because she had to bring her infant child to the RTC for all her visits, appointments and therapy for her older child in treatment.

Besides discussing the impact of their involvement, some parents took the opportunity in this question to discuss the impact of their experience in RTC on them, their child and family. For example, several discussed the emotional strain on them caused by their decision to place their child in treatment. One described feeling "guilty" for placing their child "far away in a strange place." One respondent shared her pain regarding how her child was placed:

It has been an awful experience. We miss our son badly. Losing custody so the state has the financial convenience of getting funding from the federal government is a deep festering wound. We were charged with neglect. Our names were put on the child abuser list. We fought in two courts and won, but it is very hurtful on top of dealing with a very sick child. The government does not take custody from parents who have children sick with cancer, they should not do it for emotionally sick children either. We had no support from the facility regarding this deep wound. Our son is not getting any better and the ordeal feels like it will never end.

After the child was placed into treatment, parents expressed further challenges and hardships. Respondents discussed family members deeply saddened by missing each other, while others complained that the RTC experience was negative for their child

because the child had not improved and sometimes had become worse. Some respondents discussed other challenges with the RTC including inconvenient visiting times and being allowed limited access to information on their child's treatment. Finally, one respondent expressed confusion about the impact of her involvement: "Everyone says it was important, but no one provided any concrete evidence for this. Also, our son remains angry and [manipulative] toward his therapy and us so it is difficult to judge."

Positive Outcomes

In addition to noting the challenges involved with having a child in an RTC, some respondents noted positive impacts of their involvement on themselves, their child and their child's treatment. For example, parents stated that by being involved, they had been able to influence their child's treatment, held treatment providers "accountable" and also knew how treatment had affected their child. Other respondents shared that they had learned from the experience, including their legal rights and how RTCs work. Respondents also felt the RTC provided them and their child with benefits and had led to improvements in their child's behavior and in their relationship. One parent described a child who was "a different child...the most stable EVER" after RTC and another said: "We now have a good relationship with our son. Our family is 'put back together.' It is possible to partner with treatment to raise a child."

Of the 14 respondents who noted some positive aspect of their involvement, eight of them described the benefit of their involvement as supporting them and their child emotionally. For example, parents explained how their involvement supported their child to "not feel abandoned," and instead to feel "loved, supported and cared about". Parents emphasized that their involvement, including phone contact and regular visits, allowed

for ongoing bonding and for the child to feel connected to them. Furthermore, the child knew that the parents were "there for the long haul" and they believed their presence, encouragement and support had allowed their child to succeed in treatment. Not only did their involvement help their children, parents also stated that their involvement helped them through this emotionally difficult time. One parent explained: "My involvement in my child's care at the RTC helped me feel better about having my child live away from home."

Overall parents emphasized that although it was difficult and straining on them emotionally and practically, their involvement benefited their child, thus making it worth it for them. Parents understood this was not an easy choice, but sometimes beneficial and necessary for their child. One parent summarized this sentiment as follows: "This entire experience has been a difficult as well as positive. I believe this was the right choice for my child."

Advice for Families

Respondents were asked what advice they would give to families entering an RTC. Twenty-seven parents responded to the question. Although a few respondents advised parents never to put their child in RTC, the majority provided parents with advice about how to manage the decision about placement and how to deal with placement when they were there. Thematic analysis was completed on the responses and three main themes emerged. Parents advised other families to gain knowledge, be involved in their child's treatment and to get support for themselves.

Gain Knowledge

Respondents advised parents first to educate themselves. Respondents suggested parents "learn as much as they can about their child's illness" and to research treatment options and medications, suggesting that an RTC should be a final alternative after other treatments were attempted and proved unsuccessful. Then, if RTC proved the best option, they recommended researching the facility and the types of treatment offered there by talking to other families for input and touring the facility to observe the program in action and "get a feel for staff." Several respondents gave parents numerous specific questions to ask of the director, admissions personnel and staff. A compilation of these questions is outlined in the table below.

Table 5

Questions for Families to ask RTCs

Questions regarding Staff and Treatment Team

Ask to see the detailed credentials of all owners and therapists.

What level of training will those involved with their child's care receive?

Are the teachers licensed?

Are background checks performed for all staff, and if so, who conducts them?

Questions regarding the Treatment Program

Ask whether restraint and seclusion are practiced and what the policies surrounding seclusion and restraint are. Find out what steps the staff takes to avoid restraint and seclusion.

Are all aspects of the program accredited?

How many hours are spent doing treatment related activities?

How many hours are spent in school?

Questions regarding Family Involvement Practices

Ask whether you will be able to attend treatment team meetings.

How often will I be able to visit my child?

Questions about Treatment Outcomes

Request references and quantitative information about former patients, i.e. of those entering the program, how many "graduate?" Of those, how many are successful in further education or employment. How many relapse? How many return?

Ask to receive research data that illustrates the effectiveness of the approach.

Ask what their success rates are. How do they measure them?

Be Involved

Sixteen respondents encouraged parents to be actively involved in their child's treatment at the RTC. While a few parents also encouraged involvement on a broader level, such as advocating for change in the Juvenile Justice System, the majority of respondents focused their advice on parent's involvement at the RTC itself. Respondents stated that even when they felt their involvement was not encouraged, suggested or welcomed by the RTC or their own child, parents should be proactive and become an advocate for their child. One parent recommended:

Stay on top of everything. Call the therapist weekly even if he/she doesn't call you. Check on his direct care needs like showering, clothing, vision/dental/medical checkups. Watch for signs of maltreatment. Call your

child a lot on the phone so you can assess how he's doing. Get to know the staff. Visit as often as you can. Make sure your child knows he is never off your mind.

Other parents shared this emphasis on fighting for involvement, one stating parents needed to "insist on involvement" in decision making and another calling for a need to "be pushy."

You have the right to take part in planning your child's treatment. You have a right to help decide what medications your child does or does not take. If they try to exclude you, speak up. Remind them you're still the guardian, not them. Ultimately you make the decisions, not them. If they try to intimidate you with policy hogwash, remind them of yours & your child's rights. Ask questions, take part when you can, & educate yourself on your rights.

Others recommended taking a gentler approach, telling parents to be "reasonable" and not to show "hostility" in order to work with the RTC and get needs met. "Be an advocate, but don't make people reluctant to call you (don't express hostility, pain, or the 'difficult' emotions), or you won't get called." These respondents still advocated for parents to be assertive and believe in themselves and the importance of what they can offer their child in treatment:

Be very strong and present. Do not think that because someone else is a trained professional they know better than you. They hopefully do know a lot you don't know but you know your child...do not lose sight of that.

Get Support

In addition to advising parents to educate themselves and stay involved in their child's treatment, eight respondents also suggested parents reach out for support from other parents, their family and community and from local or national organizations like NAMI, The Federation of Families for Children's Mental Health, and SAMSHA.

Respondents stated that they knew "talking with a parent who's been there helps like you wouldn't believe" and used this question to offer their own words of support and

encouragement to parents. Respondents reminded parents that the experience was "intense" but provided necessary "structure" and it was supposed to be a "positive, helpful" experience for their child. They encouraged parents stating that their involvement would help their child succeed and warned parents that it would be a "big commitment" that will bring both "joy and heartache." They also helped to put the experience in perspective as it should last a short time with focus on community integration and would be only be part of a child's continued treatment: "Think of it as a small piece in the entire treatment plan for your child."

Advice for RTCs

Respondents were asked what advice they would give to RTCs about involving families. Twenty-five parents answered this question and shared sentiments that RTCs were not doing enough to involve families and needed to "step it up." They encouraged RTCs to create or increase parent involvement practices at their agencies. Six parents urged RTCs to move beyond saying they wanted family involvement and to create policies that actually fostered family involvement. These parents told RTCs to "practice what you preach" and "really involve the families. Don't just say you do, make policies to do it. Don't keep families from being part of the team."

"Step it up"

Fifteen of the parents who answered this question provided practical suggestions for how RTCs could develop policies that would increase their involvement in their child's treatment and in the RTC itself. They suggested RTCs require frequent meetings between therapists, psychiatrists and parents. They said RTCs should allow caregivers to have direct access to treatment meetings and to ask families before decisions are made.

Respondents suggested that RTCs schedule visits at parents' convenience and make appointments far in advance, being mindful of parent schedules. When face-to-face interactions were not possible, respondents suggested psychiatrists create reports for parents on their child's medication and progress. Respondents believed that RTCs should emphasize to staff the importance of interacting with parents and create time within staff schedules for them to spend with families. Finally, many respondents believed that RTCs should provide parent education groups and workshops for families which could help parents gain the tools and training they need to be more involved and support their child in treatment as well as giving parents a way to connect to and support each other.

In addition to policy changes, respondents offered advice about how RTC staff approached and worked with parents. Overall, these parents encouraged RTCs to "ask" parents what they want and to "listen" and "pay attention to what they have to say." The respondents urged the personnel to be sensitive to parents and the many challenges they have faced with their child and continue to face by placing a child in an RTC:

[Parents] have to be totally involved and not shunned and told they are terrible and have done all this stuff wrong. They need to be supported and also have more give and take, taking into [account] both the viewpoint of the parents and the therapist.

Parents also asked for the RTC to give them reassurance so that they know "that their involvement will not jeopardize their child's placement but will facilitate their child's possible recovery" and so that they can hear from the RTC staff that their involvement is "desirable and not considered intrusive." Parents emphasized that RTCs should consider parent involvement important because the goal of treatment is to return the child at home and without consistency the child could return to an RTC. In the words

of one participant, "If nothing else, if parents are not informed about practical aftercare suggestions, and are not involved in goals, how will they be successful upon their child's return to the home and community?"

Finally, several respondents wanted to remind RTCs of the importance of their role in their child's and these families' lives and the meaning their positive contributions would have for them:

You are caring for someone's child. Their outcome is based on not only their treatment, but the positive connections they make while at RTC. Remember how great a gift this is. You can change a family's life; you can change the outcome of a child's future.

CHAPTER V

DISCUSSION

This study explored parents' and caregivers' experiences with their children's Residential Treatment Centers (RTCs) by examining two areas of family involvement at RTCs: day-to-day activities and treatment planning/implementation. The study asked parents to identify how they are or are not involved in the day-to-day activities and treatment planning/implementation of their children and their level of satisfaction with aspects of their involvement. In addition, the study explored how different factors impacted parent satisfaction and amount of involvement and heard from parents about how their involvement impacted their families and how RTCs could become more family centered.

The results of this research study suggest that (1) a range of parent and caregiver participation exists in day-to-day activities and treatment planning/implementation at RTCs with parents being more satisfied with higher levels of involvement (2) parents and caregivers' describe a continuum of experiences regarding both their amount of involvement and their opportunities for decision making which coincide with their levels of satisfaction (3) parents identify similar concerns with staff, therapists and psychiatrists (4) a number of barriers/supports impact parent involvement in these areas (5) parents and caregivers perceive multiple benefits to their involvement and (6) many possible avenues exist to enhance parent involvement at RTCs. This chapter will further summarize and synthesize these six core findings. This will be accomplished by

comparing observable patterns and themes present in the results of this study to findings highlighted in the literature review located in chapter two. This chapter will also emphasize the limitations of this study, the strengths and insight gained from this study, as well as the clinical and research implications inferred from this study.

An Expanded View of Family Involvement

This study expands on our current understanding of parent and caregiver involvement at RTCs in two domains: the day-to-day care and treatment planning/implementation of their child. Overall, respondents demonstrated a high level of participation in both of these areas at their child's RTC. For example, 68% of respondents in this study stated that they were involved in some type of day-to-activity with their child and 97% participated in some aspect of their child's treatment. Since this study asked parents and caregivers to identify the types and frequency of their involvement they had within each of these two areas, we gain a more comprehensive view of the current state of family involvement at RTCs.

Day-to-Day Involvement

Past studies on family involvement at RTCs have measured family involvement in the area of day-to-day care by "contact," "visits" or "participation in social and educational activities" (Baker, Blacher & Pfeiffer, 1993; Nickerson, Brooks, Colby, Rickert & Salamone, 2006; Robinson, Kruzich, Friesen, Jivanjee & Pullmann, 2005). The findings in this study expand on this definition of family involvement by demonstrating specific types of involvement that parents and caregivers had in the day-to-day activities of their child. In addition to phone contact and visits with their child, respondents noted a wide range of participation in various day-to-day activities. They took part in special

celebrations/holidays, meals, and sports/outings/activities. They visited school and helped with homework. Parents and caregivers helped their child with hygiene tasks, did their child's hair, bought them clothes and put them to bed. Respondents also brought children to doctor appointments and one participated in a parent education group.

The previously studied areas of visits and phone contact were also not the most common forms of participation mentioned by parents and caregivers in this study. Participation in special celebrations/holidays, meals, and sports/activities were each done by more respondents than phone contact or visits. In fact, the weekly sharing of meals, not visits, was the most common and most frequent noted type of on-site involvement by parents and caregivers. These results demonstrate the limits of defining and measuring family involvement in day-to-day care only as visits or contact and illuminate the diverse range of ways that parents feel they are involved in their child's daily lives at the RTCs. Furthermore, by asking respondents to define their own activities, we also gain a parents' perspective on how they define their involvement, perhaps shedding light on what was important to them since it is what they remembered doing. Since the level of importance of each activity was not specifically asked, however, this would be an area for future exploration.

Treatment Involvement

There is limited information in the literature on parents and caregivers' involvement in the treatment planning and treatment implementation of their child. While some studies have studied parent involvement in their child's treatment, they have typically explored parent participation in therapy (Edwards, 1992; Springer & Stahmann, 1998) and have not measured the number of other ways they could be involved in their

child's treatment from discussing treatment options and progress with providers to participation in treatment planning meetings and goal setting. McNown Johnson (1998) did explore parents' participation in "case planning" but measured it from a staff perspective, not a parents'. This study provides a broader look into family involvement in the treatment of their child by asking parents themselves to identify their involvement and by measuring certain components of treatment planning and implementation. While 92% of respondents did participate in family therapy, parents and caregivers also identified high levels of participation in other areas of their child's treatment. For example, 85% of respondents participated in treatment meetings and making treatment goals while 75% were involved in revising goals. Respondents also noted significant amount of contact with their child's therapist and psychiatrists with 97% noting in person and phone contact with the therapist and over 70% having contact with the psychiatrist. This study, however, did not ask parents the nature of this contact to further illuminate how they were participating in their child's treatment. Further investigations could explore who initiated contact as well as the purpose of the contact. Additionally, this survey only asked parents and caregivers about 8 aspects of their child's treatment, leaving out such components as their education and discharge planning, which warrant further study. This study demonstrates that past, limited definitions of family involvement in the child's treatment, such as therapy, and in the child's day-to-day activities such as contact or visits, do not sufficiently capture the range of existing family involvement opportunities at RTCs. Parents are currently involved in multiple, diverse ways at RTCs and more research is needed to continue expanding our understanding of the current types of involvement for families.

Satisfaction with Involvement

Overall, the study affirmed the sentiments of parents in previous studies (Demmitt & Joanning, 1998; Kruzich, Friesen, Williams-Murphy & Longley, 2002; Powell, 2000) that parents want to be involved in their child's care on multiple levels and the more involved they are, the more satisfied they are. It is notable, that the majority of caretakers in this study were not satisfied with the extent of their day-to-day involvement nor involvement in treatment planning. The study does point out directions to increase satisfaction. For instance, parents in this study showed higher levels of satisfaction with RTCs that emphasized and supported their involvement. Parents and caregivers in this study expressed satisfaction when they were invited and encouraged by staff to participate and were dissatisfied when they were not presented opportunities to participate in both their child's day-to-day care and their treatment planning and implementation. Respondents also expressed frustration when their participation was limited due to RTC policies such as inconvenient visiting hours or restricted access to treatment providers and treatment meetings. Finally, parents who participated in more types of involvement in their child's day-to-day care and participated more frequently in their child's treatment were more satisfied than respondents who participated in fewer ways or less frequently. Based on these results, RTCs might boost parent satisfaction by increasing types and frequency of involvement available to parents in both their child's day-to-day care and treatment.

While respondents were more satisfied with higher levels of involvement, they also expressed a range of involvement that would satisfy them. For example, some parents wanted to be notified before any changes were made in their child's treatment

while others were satisfied as long as they were notified as soon as the changes had occurred. Some parents were happy to let staff take care of day-to-day care and wanted more involvement in treatment issues while others wanted high levels of involvement in both their child's daily lives and treatment. The wide variety of responses of these parents and caregivers demonstrate that RTCs need to pay attention to the particular needs and wishes of each family to understand the types, frequency and nature of involvement that will satisfy them.

The findings that explored the relationship between certain demographic characteristics with parent satisfaction in this study agree with McNown Johnson's (2008) study that parents with children who are mandatory placements have different experiences than parents who have children who are voluntary placements. While McNown Johnson found differences in opportunities for shared decision making, this study demonstrated differences in satisfaction with amount of involvement in treatment planning/implementation. The reasons for these differences in experiences and satisfaction levels, perhaps related to differing staff attitudes or agency policies towards mandated parents, warrant further investigation.

Expanding on Baker, Blacher and Pfeiffer's (1996) findings that parent involvement did not diminish over time, this study found that parent satisfaction also did not diminish over time. In fact, parent satisfaction with regard to decision making opportunities in day-to-day care and treatment planning/implementation was higher in parents that had child placed for over 12 months as compared to parents with children in an RTC for a shorter time. This difference could perhaps be related to the fact that parents in longer placements would have more time to learn how to navigate agency

policy and culture and to develop positive, collaborative relationships with staff and treatment providers. Again, one can only speculate about the reasons for these differences in satisfaction levels related to the length of the child's placement and future investigations could explore this relationship more fully. It would also be valuable to see if parents' satisfaction levels change over time during a placement and, if so, what specifically led to their change in attitude. Overall, the small sample size of this study precluded a sufficient number of statistical tests to demonstrate which characteristics of the child, the parent and the child's placement were related to satisfaction levels on various aspects of the child's treatment and day-to-day care and these possible relationships remain an area for future investigation.

The Continuum of Involvement, Decision Making, and Satisfaction

Respondents describe a similar continuum of experiences for both their amount of involvement and their perceived opportunities for decision making. This continuum begins with total staff control and no parent input on one end and moves to increasing levels of parent voice and choice on the other end. For example, some parents stated they were "never asked" or their involvement was "non-existent" in the day-to-day care and treatment of their child while they were allowed "no input" and "no say" in decisions regarding their child's day-to-day care and treatment. On the other end, parents describe high levels of involvement with parents being able to choose the amount of their involvement and staff and parents communicating frequently and collaborating effectively about decisions regarding the care of their child. In the middle of the continuum, respondents had involvement but highlighted issues with staff and center policy that ranged in severity. Some parents experienced dismissive, inaccessible staff

who disregarded parent input or made parents feel they had to push to be involved.

Others described occasions when parent input was implemented but this occurred slowly and there was some disagreement with treatment providers about issues such as medication.

Respondents' description of a continuum of increasing involvement and decision making opportunities coincided with their satisfaction levels. Respondents who had no involvement or perceived decision making opportunities were less satisfied with their involvement and respondents expressed higher levels of satisfaction as they moved along the continuum and perceived having more opportunities for involvement, input and decision making. Respondents never expressed that they wanted total control over their child's treatment or day-to-day care, but instead noted the importance of effective communication and working with staff to care for their child. Respondents were satisfied when they were "well informed" and "contacted" with updates and when their own suggestions were "heard" and "implemented" when appropriate. Parents appreciated staff expertise in helping their child and wanted to utilize the treatment providers' knowledge to best serve their child's needs. Parents' interest in collaboration and intention to work with staff might help to ease the concerns of staff and their negative attitudes regarding increasing family involvement in the areas of decision making and direct care that were highlighted in the literature (Baker et al., 1995; Knecht & Hargrave, 2002). Mixed results regarding parent and caregivers' satisfaction levels with decision making confirms previous literature that this experience varies widely by RTC (Kruzich et al., 2002) indicating this dynamic needs further exploration by researchers and RTCs to achieve the goal of collaborative decision making, which is central to family centered practice.

Interactions with staff, therapists and psychiatrists

Parents and caregivers described a range of positive and negative experiences with staff and treatment providers at their RTC and had varying levels of satisfaction with direct care staff, therapists and psychiatrists. Although their responses often demonstrated the individualized nature of these interactions, respondents did highlight four key areas that impacted their experiences across the three professions. Respondents noted the importance of access, communication, respectful collaboration and the professional's skill to their resulting satisfaction or dissatisfaction with these interactions.

Access

Respondents' repeatedly highlighted issues with access to staff and treatment providers. They described direct care staff who did not spend time with them when they visited their children and therapists and psychiatrists who were difficult to reach or meet, which led to their dissatisfaction with their interactions. Access was a major complaint for several parents regarding the psychiatrist and could have contributed to the significantly higher levels of dissatisfaction with psychiatrist interactions than with therapists. In contrast, parents and caregivers expressed satisfaction and appreciation when staff made time to meet with them and talk with them and when treatment providers were easy to contact and offered opportunities to meet. Nearly all respondents, or 97%, had some type of contact with their child's therapist, and this increased availability likely influenced respondents' higher satisfaction with therapists.

Communication

Access to staff and treatment providers also often coincided with increased communication, which satisfied parents and caregivers. They expressed satisfaction with

staff who provided ongoing communication and updates regarding their child's progress and changing needs and similarly appreciated therapists and psychiatrists who notified them about changes to their child's treatment plan. When staff and therapists did not provide effective, open communication, respondents expressed dissatisfaction, noting experiences of being "left uninformed" by treatment providers or having psychiatrists that were "difficult to understand."

Respectful Collaboration

The most common theme mentioned by parents and caregivers was the importance of respectful and positive collaboration between them and staff, reiterating points made by parents in previous literature (Kruzich, Friesen, Williams-Murphy & Longley, 2002; Powell, 2000). Respondents expressed gratitude to staff and treatment providers who were courteous, encouraging, welcoming and supportive while they were dissatisfied with staff who were aloof and condescending and who seemed annoyed or threatened by their questions or input.

Skill

Respectful collaboration and good intentions were not always enough for respondents, however, as several complained of a lack of skill among staff and treatment providers. One respondent stated that daily care staff were not "sophisticated enough" to help their child while another stated that their therapist "could not provide concrete answers to questions." On the other hand, respondents expressed satisfaction with treatment providers and staff who had the training and ability to help their child.

Overall, respondents were most satisfied with their interactions with staff, followed by therapists and psychiatrists. This could perhaps have been influenced by the

amount of interaction they had with each of these type of staff as well as by the nature of their interactions. Issues regarding a child's day-to-day care perhaps had less emotional significance for parents and caregivers while concerns and disagreements about the child's mental health treatment and medication carried more weight, resulting in a stronger reaction to work with therapists and psychiatrists respectively.

Barriers and Supports

As in the Kruzich et al's study (2003), parents and caregivers in this study identified multiple barriers and supports to their involvement. The Kruzich (2003) study asked parents to select from a pre-determined list of barriers and support created by the respondents and that focused on RTC policies and staff interactions. In this study, however, parents were asked to list their own barriers and supports. The responses both confirmed the findings in Kruzich's (2003) study as well as touching on additional barriers and supports outside the RTC program itself.

In both studies, distance of the family's home from the facility was the most significant barrier to their involvement. Respondents in both studies also noted barriers presented by personal issues with transportation, work schedules and childcare as well as issues with the RTC itself such as poor communication, discouraging staff and restrictive policies for visiting. In addition, respondents in both studies also specified similar supports to their involvement, such as the impact of supportive, welcoming and respectful staff who provided timely communication to them. Although respondents in this study did not mention the "provision of a contact person" as highlighted as the most important support in the Kruzich (2003) study, they did share the supportive nature of certain RTC

policies including flexible scheduling of meetings, therapy and visits and financial support with transportation.

In addition to these shared barriers and supports, respondents in my study also illuminated others issues that prevented and supported their involvement. For example, several respondents discussed barriers to their participation in treatment team meetings, including access to these meetings and the purpose of the meetings. Respondents described not being invited to meetings, having to "fight" to be included or having to manage restrictive RTC policies regarding attendance at meetings in order to participate fully in treatment consultations and planning. Others felt that the meeting agendas were set by the staff as illustrated by the respondent who felt that the purpose of the meeting was to "tell [them] everything [they] had done wrong" or the respondent who felt the meeting was focused on "how my child responded to treatment and not how he was before or planning realistically about coming home." Treatment team meetings offer an opportunity for face-to-face communication and collaboration with treatment providers, two areas that parents indicated as important to them. Increasing access to these meetings and allowing family's input into the agenda would likely increase parent satisfaction at RTCs.

Although not mentioned in the question on barriers, respondents also highlighted another possible area that prevented their involvement: a lack of training and skills to know how to participate effectively on the treatment team. Several parents noted that since they did not have a professional degree in social work, psychology or psychiatry, they did not feel they had the language to contribute to their child's treatment plan or the knowledge about how treatment decisions were made. RTCs that could offer parents

education not only on their child's illness but also on the treatment process would likely ease parents discomfort in participating and increase their participation and satisfaction.

This study also highlighted supports to family involvement beyond what was illustrated in the Kruzich (2003) study. For example, several respondents noted the importance of their external support systems including understanding workplaces, family friends and church. The strongest support described by respondents was their own interpersonal strengths. They noted their perseverance, drive and love for their child to overcome challenges and do what was best for their child. Parents and caregivers expressed the will and desire to be advocates for their children and saw their own internal strength as the support for the involvement more so than any agency policy or outside support. RTCs have an opportunity to honor and build upon parents' perceived strengths, which will likely enhance family involvement and benefit the child's treatment.

Why Involvement Matters: A families' perspective

Many studies on family involvement in RTCs have demonstrated the benefits of family involvement. These studies have shown how involvement improves youth behavior and functioning, reduces their symptomatology and makes treatment more effective and long-lasting, reducing rates of recidivism (Knorth, Harder, Zanberg & Kendrick, 2008; Lakin, Bramblia, & Sigda, 2004; Leichtman, Leichtman, Barber & Neese, 2001; Prentice-Dunn, Wilson, & Lyman, 1981). While these studies provide a numerical understanding of the benefits of family involvement for children from a treatment perspective, they do not illustrate how families define the benefits of their involvement for themselves. This study, however, allowed families to explain the impact of their involvement on them and their children. In eliciting parents and caregivers'

perspectives, this study offers a broader context to understand the benefits and importance of family involvement at RTCs.

These families noted an array of benefits of their involvement. Parents felt their involvement allowed them to support their child's treatment, to learn from treatment providers and to advocate for their child when necessary. More resoundingly, however, parents and caregivers described the emotional and relational benefits of being involved. They felt their involvement helped their child to feel connected to them, even though they were separated and, thus helped the child to feel loved and supported. For example, although parents acknowledged that arranging visits could be logistically challenging and painful when they had to say goodbye and return home, the child's felt sense of remaining connected to them made it worthwhile. Parents also noted that their involvement helped them with the RTC experience. For example, knowing their child would not feel abandoned and still feel cared for helped parents to manage the guilt and sadness that came with placing their child in someone else's care. Ultimately, parents and caregivers shared a benefit demonstrated in De Boer et al.'s 2007 study, that of an improved relationship. In both studies, parents indicated that their involvement and the RTC experience allowed the child and parent to heal and find new ways of being and relating to each other.

Opportunities for Enhancing Family Involvement at RTCs

In John Powell's interview with Sandra Spencer about her experiences having a child in multiple RTCs, she summarized their most effective, appreciated practice as follows: "They asked how we did things" (Spencer, 2000, p. 40). She suggested that RTCs spend more time getting to know how their family functioned at home and how

they would like to adapt to life in the RTC. Similarly, a parent in my study emphasized the sentiment of Spencer and many respondents in my study when the parent suggested that RTCs "ask what families want." Considering the wide range of possible types of involvement in day-to-day care and treatment combined with parents' varying wishes regarding their level of involvement, it seems Spencer and this parent's advice could provide effective guidance to RTCs in how to best work with families. Instead of assuming what parents do or do not want to be involved with or guessing how they would like that involvement to occur, RTC could greet parents with some of the following questions and check-in about them on a regular basis.

Table 6

Questions for RTCs to ask Parents/Caregivers

Contact with their Child

How much contact do parents/caregivers want with their child?

Do they want this contact to be by phone or in person? How often? When?

Involvement with their Child

What type of involvement do they want?

**Be creative and give examples of opportunities for involvement with their child's day-to-day activities (such as meals, on-site activities, special celebrations, helping with homework, putting the child to bed) as well as examples of participation in their treatment (including attending meetings, collaborating on goals, learning about the child's treatment).

Contact with Staff and Treatment Providers

Who do parents/caregivers want contact with regarding their child's day-to-day care and treatment?

How often would they like contact?

Who should initiate the contact—parents or the staff?

How often would they like a report of their child's progress?

When would they like to be notified of issues?

How will decisions about day-to-day care and treatment be made to satisfy parents and in the best interest of the child?

Supports

What does their child need? What do they need?

What happened in past? What has been difficult? What has worked?

What do they hope for future? How can the RTC involve them to get them and their child where they want to be?

Increasing conversations with parents will mean staff and treatment providers need to be more accessible to parents. This in turn, will necessitate RTCs developing policies that ensure all staff members from daily care staff to therapists and psychiatrists have time built into their schedules to prioritize family contact. This will ensure that staff are reaching out to parents and available for parents when they need to contact staff. This study demonstrates that parents have a significant amount of contact with therapists, and RTCs could take advantage of that by having therapists serve as a main contact to

welcome and encourage involvement as well as to interface about issues regarding day-to-day activities and treatment. Facilities could also increase the time that psychiatrists and staff would spend with parents so they could share this role with therapists and offer parents different perspectives, areas of expertise and opportunities for collaboration. Furthermore, RTCs could use technologies, where feasible, such as three way conference calling, video conference, and e-mail correspondence to increase communication between staff and parents.

Ease the Way

The strongest message that respondents provided in this study was the extreme difficulties they faced with having their child in an RTC. Some of these challenges had to do with past issues, including failed placements and disappointments with unsuccessful treatments as well as the overall challenge of having a sick child. Parents came to RTCs after a series of setbacks and were then faced with the heartbreak of being separated from their child for long periods of time. As if that wasn't difficult enough, parents then described challenges with the RTC itself, having to fight unwelcoming staff and restrictive policies so that they could be involved in their child's day-to-day life and treatment. RTCs need to respect parents and recognize that the reality of placing a child in an RTC means that parents are already placed in an impossibly difficult position and they should not then have to fight with the people they are entrusting to care for their child.

Based on the responses in the survey, there are multiple ways that RTCs can ease the way for families to make their involvement less stressful and more rewarding.

- 1) Although RTCs cannot change the fact that they are often located far from a family home and that distance will create a barrier for parent involvement, they can ease aspects of this barrier. Vouchers for transportation costs and rides to parents without transportation; flexible scheduling for meetings, therapy and visits; and use of phone/email when coming in person is impossible would lessen the problematic issues created by distance.
- 2) RTCs and treatment providers can recognize that families are likely strained and encourage families to tap into their own support systems and offer them support groups on-site.
- 3) RTCs can offer training and educational groups to parents so they feel better informed about how to support their child, how to collaborate most effectively in their child's treatment and how to work with their child when they return home.

RTC policies that aim to increase parent involvement are only as effective as the staff who implement them. Considering previous studies (Baker et al., 1995; Kruzich et al, 2002) that have demonstrated negative staff attitudes regarding family's role in decision making and their involvement in day-to-day care as well as this study's parents who had mixed experiences with staff, RTCs need to focus on staff hiring and training to improve parent involvement. RTCs need to survey and interview staff to know their attitudes about families and then need to provide ongoing training to staff to strengthen their understanding, commitment and ability to implement family centered principles that value families as collaborative partners in the treatment of their child.

Future Areas of Research

As stated in earlier sections of this chapter, several limits to this study existed that present opportunities for future study. RTCs could prioritize the implementation of certain types of family involvement practices by ascertaining which types of involvement in the realm of day-to-day care and treatment are most important to families. Furthermore, an exploratory investigation into other aspects of their treatment involvement including education planning and discharge as well as the nature of their contact with treatment providers could provide a clearer picture of how parents are involved in RTCs today as well as opportunities for growth in this area. The mixed experiences with daily care and clinical staff and in collaborative decision making indicate these are still areas needing exploration to understand what is both preventing and allowing effective, productive interactions between RTC personnel and families that benefit the child.

A greater understanding of family involvement at RTCs would need to gather the perspectives and experiences of all family members involved. For the purposes of this study, family was defined in a limited way, as only parents and caregivers. Further investigations are needed to capture the voice of other family members, including the children in treatment as well as the siblings, grandparents, aunts, uncles, cousins, friends, and other supportive adults in the child's life. Studies that allow the families to define who is their family and shed light on each members' perspective as well as the family's perspective as a whole will be viewing the family as the unit of attention and thus, promoting family centered practice.

Another limitation to this study was that it required parents to access the survey, perhaps affecting the results since parents who were motivated to fill out the survey either were more likely to be more involved in their child's care and treatment or had a significantly bad or good experience that they wanted to share. Thus, these parents are not expressing the typical experience of parents, but have experiences outside the norm. Also, the study did not identify the RTCs or geographic area of these respondents. The unknown motivation of the parents who responded, combined with the small sample size, make it difficult to generalize these findings to all RTCs or to find statistically significant relationships between parent satisfaction with aspects of their involvement and characteristics of the child, the parent and the RTC placement. Larger sample sizes of multiple RTCs as well as individual assessments at RTCs would help to illustrate the current state of family involvement and provide feedback on how to enhance these services. While much still remains to be learned regarding family involvement at RTCs, this study demonstrates that parents and caregivers both want and need the support of RTCs to engage in the daily care and treatment of their child. RTCs, thus, have a unique opportunity to work together with a family during a highly vulnerable time in their lives to help them remain connected, heal, and grow towards a stronger future.

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APPENDIX A

HSR Approval letter

Smith College School for Social Work

November 23, 2009

Elizabeth Fenzel

Dear Betsy,

You have done a fine job with your revisions. I think the way you have revised the survey to include more multiple choice questions will make it much easier for the parents. All the changes were carefully made and we are happy to give final approval to your study.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your interesting and useful project.
Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Kate Didden, Research Advisor

APPENDIX B

IRB Approval Letter

Kentucky Cabinet for Health and Family Services

February 17, 2010

CHFS-IRB-DCBS-FY10-40

Dear Ms. Fenzel:

Your research project titled "Parents'/Caregivers' Experiences with their Children's Residential Treatment Centers" was approved by the Kentucky Cabinet for Health and Family Services Institutional Review Board(CHFSIRB) using the expedited review procedure on February 17, 2010.

In addition to all other requirements of 45CFR46.10-46.409, it is the responsibility of the researchers to:

1. obtain approval by the CHFS IRB for any modification in the research protocol or design that may increase the level of risk to a subject or a subject's confidentiality prior to implementation;
2. advise the CHFS IRB of any unanticipated problem involving a risk to a subject or another individual as a result of the research activity as soon as possible;
3. submit to the CHFS IRB an electronic copy of the final research findings and conclusions; and
4. if the study will extend beyond February 16, 2011, submit a Continuation Review Form and Status Report-to the CHFS IRB on or before January 16, 2011.

If you have any questions about any of the above, or need additional information, please contact the CHFS IRB at (502) 564-5497 x4102.

Respectfully,

Jeff Jagnow
Co-Chair

APPENDIX C

IRB Approval Letter

Sheppard Pratt Health Systems

Institutional Review Board

Chair: Faith Dickerson, PhD, MPH (phone 410-938-4359)

Vice-Chair: Gayle Hurt (phone 410-938-4873)

March 22, 2010

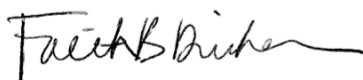
Dear Ms. Fenzel,

The Sheppard Pratt IRB has reviewed the revised application materials for your study, **Parents'/Caregivers' Experiences with their Children's Residential Treatment Centers**. Your revision has addressed the IRB concerns and the study is now approved by the IRB.

This approval covers the period from today through **June 30, 2010**. You will be notified in advance of that date to provide a renewal report.

Please note that any study modifications must be submitted to the Sheppard Pratt IRB prior to implementation of the modifications.

Sincerely,

A handwritten signature in black ink that reads "Faith Dickerson". The signature is written in a cursive style with a long horizontal flourish at the end.

Faith Dickerson, Ph.D.
Chair, Sheppard Pratt IRB

APPENDIX D

Informed Consent Form

Dear Potential Research Participant,

My name is Betsy Fenzel. I am a graduate student at Smith College School for Social Work. I am conducting a research project to learn more about parents and caregivers' experiences with their children's residential treatment centers. This study will be presented as a thesis and may be used in possible future presentations to residential treatment centers or publications on the topic.

You are being asked to participate in this study if you are a parent or primary caregiver of a child who has lived at a Residential Treatment Center (RTC) for at least three months sometime between 2005 and the present. This child must have been under 18 years old when he/she was in residential treatment.

As a participant, you must be over 18 years old and be able to read and write in English. If you choose to participate, I will ask you to fill out a confidential survey. The survey will include some general questions about you and your child as well as questions asking you to describe your experience at the residential treatment center, including a) ways in which you were involved, b) interactions you had with staff c) supports for and challenges to your involvement d) your experiences with making decisions e) how your involvement affected you and your child and f) advice you would give the agency and other parents. I estimate that the total amount of time you will need to complete the survey will be 30-45 minutes.

Participation in this study may bring up strong feelings related to you and your child's experience at a residential treatment center. In case you feel the need for additional support after participating in this study, I have provided a list of mental health resources at the bottom of this form.

Although there will be no financial benefit for taking part in the study, your participation will allow you to share your valuable knowledge and experience about residential treatment centers. It is my hope that staff and administrators at residential treatment centers will learn from this study how to better serve families and their children. You may also benefit from being able to tell your story and have your perspective heard.

Your confidentiality will be protected in a number of ways as consistent with Federal regulations. Your survey will be confidential and you should not put identifiable information, including names of you or your child, in the survey. When you contacted me to mail you a survey, I did not record your name, address or other contact information. When you mail me the survey, please do not include your name on the envelope. I will remove all identifiable information such as return addresses, names and names of

facilities from the survey. I will destroy the envelope and separate the informed consent from the surveys. I will keep both the surveys and informed consents in a locked and secure environment for three years following the completion of the research, consistent with Federal regulations. After that time, all materials will be destroyed.

As a voluntary participant, you have the right to withdraw from the study before or during the survey without penalty. Once you have mailed me your survey, I will not be able to remove it from the study since I will not be able to identify your survey among the other surveys in my study.

If you have any questions about your rights or any aspects of this study, do not hesitate to contact me at ---- or the Chair of the Smith College School for Social Work Human Rights Subjects Review Committee at (413) 585-7974.

BY CHECKING THE BOX BELOW, INITIALING IT AND WRITING THE DATE, YOU INDICATE THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION; THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS; AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Please note: When you mail me the survey using the enclosed self-addressed stamped envelope, PLEASE INCLUDE this consent form and keep the second copy for your records.

I agree to participate **Date** _____

Your Initials

Thank you for participating in this study.

Betsy Fenzel

Referral Sources

1) Mental Health America

Website: <http://www.mentalhealthamerica.net/go/searchMHA>

Phone (in crisis): [1-800-273-TALK](tel:1-800-273-TALK)

Phone: (800) 969-6642

TTY: (800) 433-5959

2) National Alliance on Mental Illness (NAMI)

Website: www.nami.org

Phone: 1-800-950-NAMI (6264)

3) Substance Abuse and Mental Health Services Administration's (SAMSHA's) National Mental Health Information Center

Website: <http://mentalhealth.samhsa.gov/>

Phone: 1-800-789-2647 Monday through Friday, 8:30 A.M. to 12:00 A.M., EST

Telecommunications Device for the Deaf (TDD): 866-889-2647

APPENDIX E

SURVEY

Thank you for your interest in participating in my survey on parents' and caregivers' experiences with their child's residential treatment center.

SCREENING QUESTIONS

Please circle your answer to the following questions:

Are you:

- 1) Age 18 or over: yes no

- 2) Able to read and write English: yes no

- 3) the biological parent, adoptive parent or primary caregiver of a child who was in a residential treatment center for at least 3 months sometime between 2005 and the present and the child was under 18 at the time of admission: yes no

****If you have answered *yes* to all of the above questions, please go on to the informed consent on the next page.**

*****If you have answered *no* to any of the questions, you are not eligible to participate in this study. Thank you for your time and interest.**



GENERAL INFORMATION

In this first part of the survey, I am going to ask some questions about you and your child who was placed in a residential treatment center (RTC).

1. Please check if you are the *parent* _____ or *primary caregiver* _____ of the child in RTC.

2. Your Age:

18-25	40-50
25-30	50-60
30-40	above 60

3. Your Ethnicity (circle all that apply):

Hispanic or Latino	Black or African American
White	Asian
Native Hawaiian or other Pacific Islander	American Indian or Alaska Native
Other (please specify):	

4. Your Annual Household Income:

Less than 25,000	60-80,000
25-40,000	80-100,000
40,000-60,000	above 100,000

5. Your Relationship Status:

Single	Live-in partner
Married	Other:
Divorced	

6. Number of Children under your care:

1	4
2	5
3	6 or more

7. Your child's age at time of placement in most recent RTC:

8. The length of time your child stayed in most recent RTC (in months):

9. Was this most recent placement mandatory or voluntary?:

10. Was this your child's first placement? Yes No
If no, number of times placed in RTC:

For the rest of the survey, if your child has been in multiple Residential Treatment Centers (RTCs), please describe his/her *most recent* placement. This survey will focus on your experiences in two areas at the RTC: the day-to-day activities at the RTC and your child's treatment. In SECTION A, questions will ask you about your involvement in your child's day-to-day activities at the RTC (such as meals, structured activities, special celebrations, and daily care for your child—doing hair, choosing clothes, etc). SECTION B will ask about your child's treatment planning and implementation (such as attending treatment meetings, setting goals and revising goals). SECTION C will ask you to share about your overall experience of being involved in these two areas at the RTC.

SECTION A: DAY-TO-DAY INVOLVEMENT

Please think about your child's day-to-day activities at the RTC (such as meals, structured activities, special celebrations, and daily care for your child—doing hair, choosing clothes, etc). Note: this does not include your child's treatment.

1. List each day-to-day activity you were involved in (up to 7) and how often you participated in each activity.

ACTIVITY	Daily	Weekly	Monthly	1-2 times
Ex. Attended school plays				x

2. How satisfied were you with your amount of involvement in your child's day-to-day care?

- 1) very unsatisfied 2) unsatisfied 3) neutral 4) satisfied 5) very satisfied

Please explain:

3. How satisfied were you with your opportunity to make decisions about your child's day-to-day care?

- 1) very unsatisfied 2) unsatisfied 3) neutral 4) satisfied 5) very satisfied

Please explain:

4. During this involvement, how satisfied were you with your interactions with direct care staff (residential counselors, house managers etc)?

1) very unsatisfied 2) unsatisfied 3) neutral 4) satisfied 5) very satisfied

5. How would you describe direct care staff's attitude about your involvement? Please give examples.

SECTION B: TREATMENT PLANNING AND IMPLEMENTATION

Please think about your child's treatment planning and implementation at the RTC. This could include attending treatment meetings, making and revising treatment goals, conversations with therapists/psychiatrists, family therapy etc.

1. Check the frequency of your involvement in the following aspects of your child's treatment planning and implementation:

Type of Involvement	Daily	Weekly	Monthly	1-2 times	Never
Phone contact with therapist					
Phone contact with psychiatrist					
Met with therapist					
Met with psychiatrist					
Attended treatment meetings					
Participated in making treatment goals					
Participated in revising treatment goals					
Attended family therapy					
Other:					
Other:					
Other:					

2. How satisfied were you with your amount of involvement in your child's treatment planning and treatment implementation?

1) very unsatisfied 2) unsatisfied 3)neutral 4) satisfied 5) very satisfied

Please explain.

3. How satisfied were you with your opportunity to make decisions about your child's treatment?

1) very unsatisfied 2) unsatisfied 3)neutral 4) satisfied 5) very satisfied

Please explain.

4. How satisfied were you with your interactions with therapist(s) regarding your child's treatment?

1) very unsatisfied 2) unsatisfied 3) neutral 4) satisfied 5) very satisfied

5. How satisfied were you with your interactions with psychiatrist(s) regarding your child's treatment?

1) very unsatisfied 2) unsatisfied 3) neutral 4) satisfied 5) very satisfied

6. How would you describe the therapist(s)' and psychiatrist(s)' attitudes about your involvement? Please give examples.

SECTION C: OVERALL EXPERIENCE

1. How would you rate the emphasis that your child's residential treatment center placed on family involvement?

1) no emphasis 2) minimal emphasis 3) some emphasis 4) strong emphasis

2. What barriers, if any, affected your participation in day-to-day activities and/or treatment planning/implementation?

For example, these barriers could be agency-based (such as a lack of policies to involve families or distance of the facility from your home) or personal (such as scheduling difficulties due to your job or lack of transportation).

3. Please give examples of what supported your involvement in day-to-day activities or treatment planning/implementation?

For example, these supports could be agency-based (such as encouraging staff or family involvement policies) or personal (such as your support system).

4. How, if at all, did your involvement impact you personally, your family, your child, your child's treatment, other?

5. What advice would you give an RTC about involving families?

6. What advice would you give other families entering RTC?

Thank you for your participation. If you know others who might be interested in taking this survey, please pass along the website, www.rtcparents.com, or for printed versions, my phone number: 410.938.4586.

APPENDIX F

Recruitment Flyer



**Attention
PARENTS/CAREGIVERS**

of a child in a Residential
Treatment Center:

This is your chance to speak and be
heard!

I am looking for participants to take a **CONFIDENTIAL SURVEY** for my study on parent's/caregiver's experiences at their child's residential treatment center.

You can participate in this study if

- 1) You are over 18 years old
- 2) You read and write in English
- 3) You are the parent or primary caregiver of a child who has been in residential treatment for at least 3 months sometime between 2005 and now.

Share your experience and help others learn from you!

- 1) Take the anonymous survey online at **www.rtcparents.com** or
- 2) Call me at **410.938.4586** to send you a printed version and a stamped/self-addressed envelope. Note: you will not have to give your name

Take the information below to fill out the survey. Thank you for your participation!

www.rtcparents.com
For print version:
410.938.4586

www.rtcparents.com
For print version:
410.938.4586

www.rtcparents.com
For print version:
410.938.4586

www.rtcparents.com
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www.rtcparents.com
For print version:
410.938.4586

APPENDIX G

Recruitment Email

Dear _____ ,

I am writing to ask for your help in recruiting for my study on parents' and caregivers' experiences with their child's Residential Treatment Center (RTC). In my study, I am hoping to collect information from a diverse sample of parents from across the country to gather a better understanding of how parents' and caregivers' are currently involved at RTCs as well as how agencies and practitioners can enhance parents' and caregivers' future involvement. Participants must be over 18, able to read and write English, and be the parent or primary caregiver of a child who was in residential treatment for at least 3 months sometime between 2005 and the present. For the study, participants will be asked to fill out a confidential survey. They can access the survey anonymously at www.rtcparents.com or they can call me at 410.938.4586 for a printed version which I will mail to them with a self-addressed/stamped envelope. If they call me for the printed version, they will not have to give their name, only their mailing address.

I have enclosed a recruitment flyer that you can make copies of and 1) hand directly to possible participants, 2) mail or email to possible participants, or 3) post in high traffic areas where possible participants will see it. Please first check with your agency to make sure you will be following any of their recruitment policies. In addition, please forward this flyer along to any of your own contacts who might be able to reach more participants.

Thank you very much for your support in recruiting for my study. If you are interested in hearing about my findings when I have completed my study, please contact me. Also, if you have any questions, do not hesitate to get in touch with me.

Sincerely,

Betsy Fenzel

APPENDIX H

Survey Website: www.rtcparents.com

SURVEY for Parents and Caregivers of Children in Residential Treatment Centers.

- [Home Page](#)

Hello Parents and Caregivers,

Please click the link below to begin the survey:

http://www.surveymonkey.com/s.aspx?sm=3A7kTnGjIFveuAakDpU6tg_3d_3d

If the link does not work, please cut and paste it to your web browser.

Thank you for your participation.

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