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CAREGIVERS' PERCEPTIONS OF ACCESSIBILITY AND QUALITY OF
SERVICES IN THE COMMUNITY FOR CHILDREN WITH MENTAL
HEALTH DIAGNOSES: A PILOT SURVEY

by

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CAREGIVERS' PERCEPTIONS OF ACCESSIBILITY AND QUALITY OF SERVICES IN THE COMMUNITY FOR CHILDREN WITH MENTAL HEALTH DIAGNOSES: A PILOT SURVEY

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Western Michigan University, 2005

This pilot study was intended to explore caregivers' perceptions of the mental health services available in the community for children with mental health diagnoses. A study-specific survey was developed to look at demographic characteristics, service accessibility, and service quality. This survey was distributed to caregivers through Michigan support groups. Returned surveys were analyzed for themes that could assist in the development of further research to improve community services for children with mental health diagnoses.

This pilot study yielded rich qualitative data. Upon review and analysis, five themes emerged: (1) bureaucratic hassles and getting the runaround, (2) closed doors, (3) support networks, (4) workers' aptitudes and ineptitudes, and (5) therapeutic relationships. These themes offer initial insight into how services can be developed to better meet needs within the community. Additionally, this study illuminated the valuable information provided by caregivers and the need for further exploration of such perceptions for the improvement of service quality and accessibility.

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CHAPTER I

INTRODUCTION

Background

Occupational therapy emerged in the mental health system of the early 1900's and was a part of the paradigm shift from "warehousing" of mentally ill persons to the mental hygiene movement and progression into dynamic treatment. These movements in psychiatric care contributed to what was considered to be a more humane approach to the treatment of mental health diagnoses. In the late 1950's, there was a movement away from institutionalization of individual's with mental health diagnoses and toward community mental health centers. Presently, community-based programs are focused on assisting individuals with mental health diagnoses in the development of skills for independent living, a goal that is relevant to the field of occupational therapy (Stein & Cutler, 2002).

As inpatient hospitalization length-of-stay decreases, there is an increase in the responsibility and partnership expected of caregivers' roles in the care of their child with a mental illness. Community services are intended to assist parents in this responsibility while acknowledging the parents' expert knowledge regarding their children. For a successful partnership to occur and facilitate optimal functioning of these children, there is a need for effective communication between parents and professional, which is facilitated by a better understanding of parents' perceptions (Scharer, 2003).

In the surgeon general's report of 1999, it was estimated that approximately 8% of children and adolescents use specialty mental health services annually and 21% of children and adolescents receive some form of mental health care each year. The report also noted that a number of children with diagnosable mental health disorders do not receive treatment. One factor related to the use of mental health services identified by the surgeon general's report is the ease of accessibility of services, and the system is likened to a maze. In addition, the surgeon general expresses the importance of tailoring services to individuals for improved quality. Community mental health systems are responsible

for assessing their services to ensure easier access to mental health services and individualized services through the system (U.S. Public Health Service, 1999).

Question Development

The topic for this research was brought to my attention during my time working with families who were consumers of various community services for children with mental health diagnoses. In a very short time, I was appalled at the number of stories caregivers shared regarding the obstacles they encountered while trying to obtain services for their children and the disappointment they felt in many of the services provided.

Even more surprising, to me, was the minimal amount of available literature regarding the accessibility and quality of mental health services in the community for children. Most literature that was available was either about inpatient mental health facilities, adult mental health services, or mental health services in other countries. Additionally, the literature often neglected to take into account the perspective of the caregiver, though this perspective was represented in the research of many other pediatric diagnoses and service concerns, including congenital heart disease (Tak and McCubbin, 2002; Rempel, Cender, Lynam, Sandor, and Farquharson, 2003), hearing impairment (Minchom, Shepherd, White, and Hill, 2003), failure to thrive (Thomlinson, 2002), and neonatal intensive care (Cescutti-Butler and Galvin, 2003). I was inclined to develop a study to explore caregivers' perceptions of the accessibility and quality of services available in the community for children with mental health diagnoses in the state of Michigan.

Research Question

What are caregivers' perceptions of the accessibility and quality of services available in the community for children with mental health diagnoses?

Purpose

The purpose of this pilot study is to investigate the operation of the Michigan Community Mental Health system as it is viewed by caregivers of pediatric consumers. This study is intended to discover how caregivers perceive the services they receive and where they see gaps in the services their children are receiving. This study is also intended to develop a model to further explore caregiver's perceptions of the accessibility and quality of community services available for children with mental health diagnoses. This survey tool may then be used for a more in-depth qualitative study of caregiver's perceptions of mental health services in an attempt to improve accessibility of services in the community and ensure that services are meeting the needs of the consumers for whom they are designed. This assists the community mental health system in the mission of providing services that will promote the development of these children into healthy, productive members of society.

Variables

In completing this study, certain variables were defined in order to increase understanding of the information provided. Definitions were developed by the researchers and are study specific.

- ♦ Caregiver: For the purpose of this study, a caregiver is a biological, adoptive, or foster parent of a child with whom the child lives and who provides for the child's immediate needs.
- ♦ Perception: An individual's view that is based on cognitive and emotional experiences.
- ♦ Mental Health Condition: A diagnosis given to an individual based on criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV).
- ♦ Children: For the purpose of this study, a child is an individual older than zero and eighteen years of age or younger.
- ♦ Community Services: Multidisciplinary interventions provided to the child and family in relevant environments.

- ♦ Quality: For the purpose of this study, quality refers to the degree to which relevant outcomes are acquired for children and their families.
- ♦ Accessibility: The quality of being able to easily gain access.

Benefits

It is expected that this study will assist health professionals in beginning to understand where gaps in or blocks to service may occur so that a plan can be made to remedy such gaps or blocks. In addition, this study is intended to increase professionals' understanding of caregivers' perceptions to facilitate better communication between caregivers and the professionals working with their children. This study provides a specific opportunity for occupational therapists to determine those roles for which they are qualified that are in need of being filled, so as to better serve the population of children with mental health disorders. This is a field in which occupational therapy has historically played a role, and there are still needs that can be met by occupational therapists in the realm of pediatric mental health.

CHAPTER II

REVIEW OF LITERATURE

Mental Health Services: Issues in Accessibility

Studies have been completed looking at numerous possible barriers to access of mental health services. Chun-Chung Chow, Jaffee, & Snowden (2003) completed such a study to examine racial/ethnic disparities in mental health service access and use at different poverty levels. The study was completed in New York as a retrospective data analysis, and the population included clients of mental health services in both low and high poverty areas. Researchers reviewed state mental health data to obtain information on diagnosis during a seven-day period. Census information was used to determine poverty level. Bivariate analysis of association and logistic regression analyses were used to analyze the data (Chun-Chung Chow, Jaffee, & Snowden, 2003).

Chun-Chung Chow, Jaffee, & Snowden (2003) discussed that there are racial and ethnic disparities in access to mental health services and the types of services utilized and/or received, and they noted the importance of further research into how and why access to care and quality of care are impacted by racial/ethnic differences in order to address such disparities. Researchers speculated that some disparities might be correlated with cultural beliefs and the stigmatization of mental health issues. For example, minority groups were more likely to use emergency psychiatric services and African Americans in particular were more likely to come into services through the legal system. In an attempt to begin addressing the disparities, researchers recommended outreach and public education to increase the use of non-emergency mental health services and the encouragement of voluntary service access. They noted that accessibility might also be improved by tailoring services to meet the needs of various minority groups, as the population dictates (Chun-Chung Chow, Jaffee, & Snowden, 2003).

This study was specific to the New York area, and it is notable that the large sample size could lead to Type I error. Additionally, the review of census data provides an awareness of disparities but only allows for speculation as to the possible reasons for

those disparities. Therefore, as researchers recommended, there is still a need for further research to determine how disparities in mental health use may be remediated.

Sturm, Ringel, & Andreyeva (2003) completed an observational analysis study of how state of residence affects mental health service use. Researchers analyzed data from the National Survey of American Families in both 1997 and 1999, specifically regarding use of mental health services and number of visits among users; need for mental health care based on sample items from the child behavior checklist; unmet need; and need among users of mental health services. All children with complete survey information were subjects of the study, for a total of 45,247 children. Data were analyzed using descriptive statistics, t-tests, and logistic and linear regression models (Sturm, Ringel, & Andreyeva, 2003).

Researchers found that there were geographic disparities in mental health service use even when race/ethnicity and income were controlled for. Overall, it was found that states that had an increase in service use also had an increase in intensity of service, and states that had lower service use did not have lower levels of need. Due to the disparities that existed even after controlling for other variables, researchers concluded that variations across states are more likely related to state policies and health care markets than sociodemographics, but both of these sets of characteristics impact service in varying ways among states, indicating a need to look at disparities in service at a state level to determine ways to remedy difficulty with accessibility (Sturm, Ringel, & Andreyeva, 2003).

This study was based on a survey that relied on caregiver report regarding the use of services and assistance received rather than documentation from mental health professionals. Additionally, only sample questions from the Child Behavior Checklist were used to determine need for mental health services, nullifying validity and reliability statistics that hold true for the instrument when used in its entirety. Finally, the large numbers once again could lead to Type I error.

In their New Haven, Connecticut study, Briggs-Gowan, McCue Horwitz, Shwar-Stone, Leventhal, & Leaf (2000) examined child psychiatric disorders in pediatric settings and identified factors associated with parents' use of pediatricians as resources concerning emotional/behavioral issues and the use of mental health services. They used

a semi-structured interview with caregivers of children in pediatric practices throughout New Haven who screened positive for behavior problems along with 50% of caregivers of children who screened negative for behavior problems. Data was collected using the Diagnostic Interview Schedule for Children, Revised along with questions regarding consultation with a doctor about behavior concerns and use of mental health services. Data was analyzed using correlational analysis and multivariate logistic regression models (Briggs-Gowan, et al, 2000).

In this study, researchers found that over half of parents who identified their child as having a disorder did not discuss these concerns with their pediatrician. This was true even though discussing concerns with a pediatrician was correlated with a higher likelihood of obtaining mental health services. That said, researchers did note that half of those who reported discussing problems with a pediatrician still did not receive mental health services. Given this information, researchers concluded that there is a need for increased identification of pediatric mental health concerns by pediatricians for improved accessibility to mental health services, recommending training for pediatricians regarding the identification of mental health issues and referral to mental health services. To assist in the referral process, researchers also proposed increased communication and collaboration between pediatricians and mental health professionals (Briggs-Gowan, et al, 2000).

As with any caregiver report, there is always the possibility of parental stress leading to over-reporting of symptoms or the possibility of social stigma leading to underreporting of symptoms. In addition, the results of this study are correlational but specific cause and effect cannot be determined.

Walders, Childs, Comer, Kelleher, & Drotar (2003) completed a study in which conclusions regarding pediatrician training in mental health diagnosis were similar to those discussed by Briggs-Gowan, et al (2000). This study examined the frequency of barriers to mental health referral according to pediatric primary care physicians and attempted to identify factors related to perception of referral barriers for patients with managed care coverage. A national sample of primary care physicians from large research networks was invited to participate. Those who agreed (n=539) were sent the

Clinician Practice Questionnaire, and all returned surveys (431) were analyzed using descriptive statistics and bivariate analysis (Walders, et al, 2003).

Some notable barriers to mental health service referral discussed in this study included the lack of availability of pediatric specialists, difficulty or delay in getting an appointment, and specialist limits (i.e. not accepting Medicaid). These barriers were more notable for managed care patients than for fee-for-service patients. Due to the increased responsibility managed care places on primary care physicians in the identification of mental health diagnoses and referral to appropriate services, researchers concluded that further training is necessary. Additionally, the researchers noted the need for increased availability of mental health services in the community and increased physician awareness of such services, as fewer barriers to mental health service referral were reported in communities with increased availability of services (Walders, et al, 2003).

Though this study explores barriers to mental health service referral, it does not take into account the patient perspective of barriers. Additionally, the barriers to referral were pre-selected and physicians were asked to identify whether they were in fact barriers. Open-ended questions may have allowed for further barriers to be explored.

Overall, researchers have noted barriers to access and disparities in the use of the mental health system. Researcher recommendations to improve access and reduce disparities include public outreach and education (Chun-Chung Chow, et al, 2003), designing services to meet the needs of the specific market (Chun-Chung Chow, et al, 2003; Sturm, Ringel, & Andreyeva, 2003), physician/professional education regarding diagnosis and referral for mental health disorders (Briggs-Gowan, et al, 2000; Walders, et al, 2003) and increased communication between pediatricians and mental health professionals (Briggs-Gowan, et al, 2000).

Caregivers' and Families' Perceptions of Accessibility and Quality – Adult Mental Health Services

There was a fair amount of literature available regarding mental health services for adults with mental health diagnoses, and this literature included studies that

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incorporated caregiver perspective for a better understanding of how services could be designed. Kosloski, Schaefer, Allwardt, Montgomery, & Karner (2002) completed a survey study of caregivers to gain a better understanding of the role of culture in the use of respite services. The study surveyed caregivers of Alzheimer's patients in six states who were participating in the Alzheimer's Disease Demonstration Grants to States (ADDGS) Program. All caregivers who had utilized in home day care or respite, had complete demographic information on file, and had phone contact information on file were invited to participate, and approximately 80% of eligible caregivers (n=315) completed phone interviews. The amount of respite services use by the caregiver was documented, as was socioeconomic status, and questionnaires were utilized to ascertain caregiver's attitudes and beliefs regarding caregiving and their evaluation of service delivery. Data were analyzed using ANOVA and bivariate analysis (Kosloski, et al, 2002).

In this study, researchers found that Hispanic/Latinos were more likely to report communication difficulties with respite services, yet they perceived greater access to respite services than did African American and White caregivers. Researchers speculated that his might be an indicator of success of the ADDGS to establish services to address needs of minority groups. Hispanic/Latinos were also less likely to feel guilty about using respite services and demonstrated significantly higher family values than African Americans and Whites. Overall, family values had a positive correlation to the use of respite services, as did respect. Researchers found that respite services are, then, more likely to be used when there is a focus on respect of elders and family values. Additionally, service use increases when access is facilitated through other programs. Researchers concluded that caregiving attitudes and beliefs were related to service use. Therefore, it may be possible to increase service use by addressing caregivers' attitudes and beliefs (Kosloski, et al, 2002).

In order to address caregivers' attitudes and beliefs, further studies would be needed to better understand such needs and to determine how services could be tailored to those needs. It is notable that results of this study were correlational, and direct effects could not be determined. Additionally, there may be other extraneous variables that may also correlate with differences in respite service use. Finally, this study was limited to

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one particular program, for which one of the goals was to address the needs of minority groups, which may explain data, such as the increased use of services by both Hispanic/Latinos and African Americans.

In an exploration of the quality of services, Adam, Tilley, & Pollock (2003) sought to describe the role of community psychiatric nurses (CPN) in Scotland in caring for people with enduring mental disorders and to identify means by which CPN's encourage people to participate in their own care and treatment, all as perceived by the nurse and the people themselves. Researchers employed a semi-structured interview focused on critical incidents to obtain data from the 14 patients selected by CPN's as individuals with whom the most empowering work was done. Data was analyzed using a qualitative thematic analysis approach (Adam, Tilley, & Pollock, 2003).

This study was completed at a time when mental health services were being focused more in the community and less in hospitals. Within the study, clients noted positive relationships with community psychiatric nurses, and, based on clients' reports, these rapport skills seemed to be of greater value to the clients than were specific clinical skills. Clients noted the value of talking to their CPN's about various issues to work through problems, express emotions, and maintain relationships – talking in a way they could not with others in their lives. Some felt the CPN really helped them to see things in a new way. CPN's were noted to provide clients with a sense of connectedness when they were in an otherwise lonely place, and people valued being valued by CPN's. They were noted to desire to be listened to, to not be judged, and to be taken seriously. Conversely, clients expressed feelings of being minimized when they felt their CPN was not giving them time or when they received less personal contact than they felt was needed in a situation. Other aspects of service clients found valuable included regularity, consistency, and stability of services; and the advocacy role CPN's played when dealing with doctors (Adam, Tilley, & Pollock, 2003).

This was a relatively small study completed in Scotland, and further studies would be required in other areas to increase generalizability of results. The selection process of the subjects also reduces the generalizability of results, as nurses selected the case in which they felt their most empowering work was completed.

In continuing to look at the needs and wants of consumers and their families, Tryssenaar, Tremblay, Handy, and Kochanoff (2002) sought to describe the complex factors involved in growing older within the community for persons with serious mental illness from the perspective of family members. This phenomenological study was completed in northwest Ontario in an urban center. Three advocacy and support agencies provided contact information for family members interested in participating in the study to researchers who then mailed information about the study. If the family members consented to participation and their family member with serious mental illness was living in the community, was at least 35, and had at least a 15 year history of serious mental illness, a semi-structured life history interview was conducted, audio taped, and transcribed (n=11). Data was analyzed first through independent coding and then themes were compared by the group for refinement (Tryssenaar, et al, 2002).

The five themes of lifelong impact of illness, occupational performance problems, the family member as case manager, systemic barriers, and the impact of growing older were identified in this study. Families were noted to identify blessings of having the individual with serious mental illness in their lives. However, the emotional and physical health of family members was impacted. Grief over the loss of what would not be and challenges of individuals with serious mental illness fulfilling life roles impacted family lives. Family members expressed their role in ways that made them daily supports, advocates, and support workers. They took on these roles to ensure both safety and better quality of life for the individual with serious mental illness (Tryssenaar, et al, 2002).

Occupational performance issues were noted in self-care, productivity, and leisure by family members who also noted a lack of needed social supports. While still being aware of occupational performance issues, family members also acknowledged the importance of recognizing small accomplishments and providing purpose with individualized programs. Legislation and limitations of community services were also noted as barriers to life participation. These concerns related to monetary issues, minimal service availability, and decreased acknowledgment of family members' roles in legislation and services. Family members did acknowledge the importance of a support group in facing daily challenges (Tryssenaar, et al, 2002).

The aging process concerned family members, both as it pertained to the individual with serious mental illness and as it pertained to the time at which they would no longer be there as the primary support for their family member. Individuals with serious mental illness were often noted to mature or improve over time, but family members still expressed concern regarding independent living. Overall, the need to acknowledge and utilize the expertise of family members regarding individuals with serious mental illness was noted. Additionally, researchers noted the need for more individualized service programming, intervention addressing family members' grief/loss, and transition related planning (Tryssenaar, et al, 2002).

One major limitation of this study is that it was completed at a time of upheaval in the local mental health system, which may have led to greater stress at the time of reporting related to the current state of the system. Additionally, the study was completed in a very specific area of Canada, and the serious mental illness of family member's was predominantly schizophrenia, limiting generalizability of the study.

Pejlert (2001) also completed a study looking at family members experiences when relatives had severe mental illness. The phenomenological study, completed in Sweden, sought to illuminate the meaning of parental care-giving in reference to having an adult son or daughter with severe mental illness living in a care setting. Caregivers of a specific group of adults with mental illness who had moved together from a psychiatric ward to a home-like setting and then to a group dwelling participated in narrative interviews in which they were asked to discuss their past, present, and future relationship with their child and their feelings. Transcribed interviews were analyzed for themes using phenomenological hermeneutic analysis (Pejlert, 2001).

Pejlert (2001) identified five themes: (1) living with sorrow, anguish, and constant worry; (2) living with guilt and shame; (3) being in a relationship with nurses/care – both comfort and hardships; (4) coming to terms with difficulties; and (5) hoping for a better life for their son or daughter. It is notable that within the interviews, parents were noted to cut life into two segments: pre and post the child's diagnosis with mental illness. There was sadness for the loss of what was in childhood and the potential for the future that was lost upon diagnosis. Parents struggled with obtaining, understanding, and accepting information while dealing with their loss. They also noted

a continued care-giving role and endless worry, despite their child living outside of the home. Parents were also noted to cling to psychosocial factors that may have contributed to their child's mental illness. They were focused on how they had caused the mental illness, and comments reflected their feelings of guilt. This guilt extended to how the diagnosis impacted their parenting of their other children as well (Pejlert, 2001).

While parents expressed both positive and negative reflections of the nurses providing care to their child, there was a perceived competition for the parental role. Parents noted difficulty having their suggestions heard, concerns with the care provided to the child while having limited authority to change the care, and concern for the lack of purpose provided in activity. The relationships with nurses seemed to go through ups and downs with changes in care settings. When trying to deal with such difficulties, parents noted a number of useful strategies and supports. Family, church, friends, and support groups were considered invaluable. Parents also noted that taking an active advocacy role and staying updated on their child's functioning was important. Researchers in this study concluded that the role of family in the care of individuals with mental illness needs to be acknowledged. This finding is consistent with previous studies. With that in mind, it was also concluded that methods to support, inform, and cooperate with parents need to be developed while still maintaining clients' rights (Pejlert, 2001).

Pejlert (2001) noted that this is one interpretation of the data collected and that other interpretations are possible. Additionally, the study was noted to follow a very difficult transition, which may have tainted overall experiences. This particular study was completed not only in a very specific area of Sweden but also with a population that had been through a unique set of circumstances, which decreases generalizablity of the study.

Studies of caregiver and family perception in adult mental health have been carried out in a number of countries. Despite differences among the countries, some issues discussed are reflected throughout the literature. Caregivers consistently expressed a desire to be taken seriously as a member of their family member's team and to be utilized for the experts that they were regarding their family members (Adam, Tilley, & Pollock, 2003; Tryssenaar, et al, 2002; Pejlert, 2001). Respect from health professionals and as a focus of services also emerged as an important quality (Kosloski, et al, 2002;

Adam, Tilley, & Pollock, 2003; Pejlert, 2001). Finally, caregivers were noted to value support groups and other social support systems (Tryssenaar, et al, 2002; Pejlert, 2001).

Caregivers' and Families' Perceptions of Accessibility and Quality – Inpatient Mental Health Services

Several studies have been completed in mental health inpatient/hospital facilities looking at caregiver and family perspectives of services provided and further needs they may have. In one such study completed in Australia by Jubb & Shanley (2002), researchers looked at how families evaluated existing services at a secure acute mental health ward. Survey research was completed using the Needs Assessment of Caregivers/Families Questionnaire to elicit views regarding information/health education, contact with health professionals, and satisfaction with services. The survey was sent to patients' next of kin following admission if the patient consented (n=54). Returned surveys (n=14) were analyzed using descriptive analysis and content analysis (Jubb & Shanley, 2002).

Regarding information and health education, some of the caregivers who participated in this study expressed concerns that information provided by the staff was incomplete or impractical. More than half of the families felt that further education and information should be provided regarding potential treatment, illness information, and legal considerations. Additionally, while the value of caregiver input has been established previously, researchers found that few families felt involved in the care of the family member both by being informed and by being asked for information only family could provide. On a related note, families did not report high levels of satisfaction with services, and staff attitudes were noted to be part of the problem. Families noted a need for greater levels of emotional support from staff (Jubb & Shanley, 2002).

Researchers concluded that educational information should be developed for families to decrease their confusion and frustration. They also felt this would help to increase overall positive outcomes. Additionally, researchers speculated that improved staff attitudes could lead to more open communication and more of a partnership of care

than secure wards traditionally allow. In-house support groups were also recommended to address caregiver's needs for emotional support (Jubb & Shanley, 2002).

This particular study was designed to improve the services at a specific facility in Australia, limiting generalizability. Additionally, the study does not address perceptions of or needs within services in the community before or after the inpatient hospitalization.

Scharer (2002) completed a similar study exploring what parents need and want from mental health professionals during child psychiatric hospitalization in the United States. The qualitative study was conducted in two child-psychiatric units using maximum variation sampling. Initial inclusion criteria were that children had to be 12 or younger and hospitalized in a child psychiatric unit, parents had to speak English, and consent to participate had to be obtained. Later in the study, willing participants were included on the basis of initial criteria as well as demographic characteristics for variation. Intensive interviews were audio taped and transcribed, and content analysis was completed. Needs of caregivers were classified into the three categories of information, instrumental support, and emotional support, the latter two applying to both parents and children (Scharer, 2002).

Areas of need regarding information included diagnosis, prognosis, problems, and community services. Parents noted difficulty obtaining information regarding pre-hospitalization options for community services, feeling they were left to find out about services independently. Upon hospital admission, parents wanted more information regarding the hospital to which their child was being admitted and access to the records regarding their child's stay, their diagnoses, and the implications. In planning for discharge, parents were interested in assistance dealing with the transition back to school and communicating with school personnel. Overall, parents felt that they should be provided with information for which they may not know to ask, placing a responsibility on staff to be aware of information that is valuable to parents. In addition, parents noted that information should be presented more than once, due to the emotional nature of hospitalizing your child (Scharer, 2002).

Needs expressed for instrumental support included lodging while the child was hospitalized, improved access to community services, easier access to their child during hospitalization, and assistance for the physical needs of their child. Regarding service

availability, parents voiced frustration with both availability of and accessibility to services. In addition, they felt that their concerns were minimized by health professionals when they were seeking services (Scharer, 2002).

Parents expressed a need for caring staff that could meet emotional needs. For parents' emotional needs to be met, their children had to be well cared for. They expressed a need to feel the staff was compassionate toward them, their children, and the other children in the hospital. In addition, parents noted that it would be valuable to be connected to parents who had been through what they were experiencing so as to be provided with emotional support (Scharer, 2002).

Overall, the results of Scharer's (2002) study were similar to those in the study by Jubb & Shanley (2002). Further information, increased parent-professional communication, and support systems were desired in each situation. That said, further studies are needed to demonstrate generalizability of these results. Additionally, a more in depth look at concerns with accessibility and quality of community services mentioned in Scharer's (2002) study is warranted.

Puotiniemi, Kyngas, & Nikkonen (2002) designed a study to analyze and describe the resources of parents with a child in psychiatric inpatient care. The survey research was completed in 19 hospital psychiatric units in Finland, and all parents of children in inpatient care were invited to participate. The questionnaires were distributed to caregivers through contact persons at the hospitals for confidentiality purposes. Returned surveys were analyzed using frequencies and percentages, chi square analysis, and content based analysis (Puotiniemi, Kyngas, & Nikkonen, 2002).

Emotional support and the need for information again emerged as themes. Researchers found a positive correlation between the receipt of emotional/instrumental support and coping abilities. Support for bringing up the child with mental problems was also connected to more positive coping. Needs for emotional support were identified when caregivers noted the importance of encouragement from health professionals as opposed to focusing only on problems, and they also expressed a desire for open communication with healthcare personnel, including discussions about their issues around the situation but not directly related to the child in care. Additionally, parents expressed their need for their role to be valued and a desire for greater empathy and

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understanding. In line with their roles being valued, caregivers desired to be collaborators in their children's' care to ease the transition out of the hospital, noting needs for practical recommendations for both general upbringing and crisis situations (Puotiniemi, Kyngas, & Nikkonen, 2002).

The low response rate to this survey is one limitation of the study. Researchers noted a miscommunication between themselves and the contact persons that may have led to the lower response rate. Additionally, they noted the presence of multiple studies being completed at the same time, which may account for some difficulty with returns. Again, the study was small and limited in scope, but it continues to contribute to the body of knowledge that is being built regarding child psychiatric inpatient hospitalization.

Shields, Kristensson-Hallstrom, & O'Callaghan (2003) took the caregiver perception studies one step further to compare the perceptions of caregivers to those of the staff at a pediatric hospital in Sweden. The survey research was completed using a convenience sample to examine the differences between the perceptions of the needs of parents of hospitalized children held by staff and parents. Staff and parents from all hospital units but intensive care were invited to participate in the study. The Needs of Parents of Hospitalized Children Questionnaire was used with parents and adapted for use with the staff. Frequency analysis and chi-square comparisons were used to analyze the data (Shields, Kristensson-Hallstrom, & O'Callaghan, 2003).

On the survey tool, which asked caregivers and staff to rate statements for importance, needs fulfillment, and independence of caregivers, staff members were more likely to rate aspects of care as important than were parents. Additionally, staff members were also more likely to perceive needs as being fulfilled than were caregivers. Caregivers more frequently responded that they could independently meet needs, while healthcare professionals felt caregivers needed more help. Researchers did hypothesize that caregivers expressed higher levels of independence due to a lack of awareness of service and supports available. They concluded that even when staff is sensitive to parent needs, they can still benefit from education and information regarding those needs and their fulfillment, specifically from the caregiver perspective (Shields, Kristensson-Hallstrom, & O'Callaghan, 2003).

Once again, this study was completed in a single hospital in another country (Sweden), limiting generalizability of results. Additionally, the study was not directed specifically at mental health services. Researchers also noted the need for studies with a larger population to be completed to allow for sub analysis of departments within the hospital to determine if specific departmental characteristics impact the results (Shields, Kristensson-Hallstrom, & O'Callaghan, 2003).

While each individual study of caregivers' perceptions of pediatric inpatient mental health services has limits related to generalizability, themes once again emerged consistently through the literature that warrant consideration. Provision of information to caregivers was noted as lacking (Jubb & Shanley, 2002; Scharer, 2002) but necessary (Jubb &Shanley, 2002; Scharer, 2002; Puotiniemi, Kyngas, & Nikkonen, 2002.) As with the needs of caregivers and family members of adults with mental health problems, the need for support groups was also acknowledged by researchers studying inpatient mental health services (Jubb & Shanley, 2002; Scharer, 2002). Caregivers were also noted to desire open communication and a partnership in their child's care (Jubb & Shanley, 2002; Puotiniemi, Kyngas, & Nikkonen, 2002). Finally, as with adult mental health services, the importance of acknowledging and utilizing caregiver perspective in the provision of services was noted (Shields, Kristensson-Hallstrom, & O'Callaghan, 2003).

Caregiver's and Families' Perceptions of Accessibility and Quality – Pediatric Mental Health Services

While there are limited studies looking at caregivers' perceptions of pediatric mental health services, literature does exist looking at accessibility, treatments, and service qualities. Starr, Campbell, & Herrick (2002) completed a study that set out to examine the attitudes of parents or guardians of children and adolescents five to nineteen years of age regarding the use of mental health services. The survey study was completed in a rural town in southeast United States. Potential participants were identified as they came into WIC (a county health facility) and/or a pediatrician's office at which time informed consent was obtained. Researchers administered the Expectations of Mental Health Survey face to face, and collected data was analyzed using

descriptive statistics and percentage of agreement/disagreement (Starr, Campbell, & Herrick, 2002).

Caregivers expressed concern about what others may think if they accessed the mental health system for their children. Many even felt others would disapprove of accessing the system. Caregivers were also concerned about the possibility of others finding out their child was receiving mental health services, and in some cases caregivers felt their child would not be open to mental health services. Many caregivers felt their child would not be respected or cared for by mental health professionals, and some were unsure if mental health workers would be trustworthy (Starr, Campbell, & Herrick, 2002).

Even with certain negative impressions of mental health care, many parents reported that they thought seeing a mental health professional would help their child grow up healthy and that they would feel good about taking their child for a visit. However, cost was noted to be a limiting factor for many parents regarding mental health care receipt. And while caregivers did not perceive problems getting an appointment or knowing where to go for care, less than half of caregivers were satisfied with mental health services available for children. Researchers did find that caregivers who had previously accessed the mental health system were more likely to have positive outcome expectations regarding the services (Starr, Campbell, & Herrick, 2002).

Ultimately, caregivers in this study had less trust in the relationship component of services but greater trust in the clinical skills of mental health professionals (Starr, Campbell, & Herrick, 2002), which is the opposite of the characteristics Adam, Tilley, & Pollock (2003) found to be most valued by individuals working with community psychiatric nurses. In an attempt to increase service use and the ability of mental health professionals to meet clients' needs, researchers recommended further exploration of what caregivers look for in a trustworthy provider. Researchers also suggested that mental health professionals work to reduce the stigma associated with mental illness to increase the likelihood that individuals would access mental health services (Starr, Campbell, & Herrick, 2002).

One major limitation to this study is that children accompanied their caregivers to the survey interview, which may have impacted the caregiver responses to the questions.

Chavira, Stein, Bailey, & Stein (2003) designed a study to illicit parents' attitudes regarding pharmacological and psychosocial treatments for childhood social anxiety and to increase professionals' understanding of factors related to these attitudes. Researchers utilized survey tools and interviews to complete their research. Families were randomly selected from a pediatric primary care mailing list and sent a brief questionnaire list. Those who returned the questionnaire and then completed a second phase phone interview were included for data analysis. The Anxiety Disorders Interview Schedule, a supplemental section regarding mental health utilization and parent psychiatric information, the Social Anxiety Scale – Children, the Social Anxiety Scale – Adolescents, the Screen for Child Anxiety Related Emotional Disorders, and a modified treatment attitudes survey were used in this study. Data was analyzed using factor analysis, multivariate analysis of variance, and mean scores (Chavira, et al, 2003).

Parent responses overall demonstrated higher opinions of counseling over medication in the treatment of social anxiety disorder. Parents did not demonstrate a negative attitude towards medication, merely a neutral one. Researchers found that mental health treatments were more accepted by families who had received previous treatment. Families were also more likely to be accepting of treatments, whether the treatment was medication or counseling, when they were informed about the treatment (Chavira, et al, 2003).

Though minorities were underrepresented in this study, they were noted to report more negative attitudes towards treatment in general than white Americans. Researchers speculated this could be related to cultural stigmas and negative outcome expectations that have been previously reported as barriers. Authors noted the need for studies that look at the perceptions of ethnic minorities more closely. In addition, further research on the impact of parental attitude regarding treatment has on treatment success was recommended.

One limit to this study is that the parents that did participate were predominantly white Americans with college degrees, a fact that may limit generalizability.

Arborelius & Bremberg (2003) developed a study to examine how "strained mothers" (p. 169) perceive the support they receive from Swedish child health nurses. The qualitative study was completed using an open-ended critical incidents interview.

Three child health care (CHC) facilities were identified in a low-income area from which the first 24 Swedish speaking mothers who were enrolled with newborn babies and were classified as strained were invited to participate. Following verbal and written provision of information and consent from mothers, a psychologist conducted the interview regarding visits with nurses. The interviews were then transcribed and analyzed to distinguish five themes (Arborelius & Bremberg, 2003).

Mothers were noted to appreciate clear answers and well-explained information in their contacts with nurses. Some mothers commented on emotional support by nurses as well, which was exemplified by listening skills and demonstrated interest in the clients. The mothers were also noted to appreciate positive role support, exemplified by the nurses giving mothers credit for a job well done or showing he or she believed in the mothers' abilities. Mothers who had positive perceived interactions with their nurses also had more positive outcomes with their infants and fewer depressive symptoms (Arborelius & Bremberg, 2003).

Mothers did note times when they experienced negative feedback from the nurses regarding their role with the child, as though dismissing their concerns and their abilities to care for their child. This was a strain for the mother. Additionally, mothers noted times of discomfort when they felt they had to do something a certain way to please the nurses. The conflict for the nurses is that they need to both build up the mother so she feels better about her abilities and present childcare ideas and concepts in a non-threatening way (Arborelius & Bremberg, 2003).

Researchers did note limitations to the study. First of all, the criteria utilized to categorize a mother as strained were not validated, but were, instead, developed based on CHC nurses' experiences with strained mothers. Secondly, the retrospective nature of the interviews could make it difficult for mothers to recall specific incidents and to not have previous perceptions altered by experiences between the visits and the interview (Arborelius & Bremberg, 2003).

Salmon, Hook, & Hayward (2003) completed a similar study designed to explore parents' views of a health visiting position in infant mental health. The qualitative study was completed in England and looked at the perceptions of parents who had direct contact with the individual in the specialized health visitor position, the other health

visitors, and the health/social care managers who referred to the service. The first 12 families to be referred to the service were invited to participate in the study, and they were then interviewed regarding the specialist health visitor position. Transcribed interviews were analyzed using categorization and thematic analysis (Salmon, Hook, & Hayward, 2003).

The specialist health visitor was to work with children ages one to four and their families on a one-to-one basis. The post was designed specifically for children who presented potential mental health problems to help parents deal with issues. Parent perspectives explored included difficulties with the child prior to the specialist health visitor, accessibility of the visitor, assistance provided, how the assistance worked, and if they were supported through the changes. Parents consistently noted positive qualities of the specialist that were tailored to their needs in their interviews. The consistency and frequency of support throughout interventions as well as the promptness and convenience of the services were noted as quality parts of this service that made it better than other services. Health professionals also noted promptness of service as a positive quality and most said they would use the service again. Once again, empathy and listening skills were identified as important qualities in professionals. Caregivers did note some frustration when they felt the visitor offered only ideas they had tried previously, but, through the supportive service, they were willing to try again (Salmon, Hook, & Hayward, 2003).

This study was designed for the purpose of exploring the usefulness of a particular service. Though the generalizability is limited, there is, again, a replication of many characteristics previously noted as valuable in caregivers and services.

Lehman (1996) examined the nature and extent of support families received from their informal social networks and from paid professionals as well as how helpful those types of support were in meeting the needs of the child and family. The survey study was completed in Oregon, using a random sample of parents form the Oregon Family Support Network. Self-administered questionnaires were mailed to parents, and returned surveys were analyzed using descriptive statistics, t-tests, chi-square analysis, Pearson Correlation Coefficients and Friedman Two-Way Analysis of Variance by Ranks (Lehman, 1996).

More than one quarter of the participants in this study did not perceive that they had received any functions of service coordination identified by Lehman as forms of professional support, and very few participants reported receiving any self-advocacy education. It was found that children aged three to ten received fewer aspects of service coordination than did eleven- to eighteen-year-olds. Lehman (1996) also found that functions of service coordination for emotional/behavioral disorders were most frequently provided by school personnel. Overall, parents expressed stress and difficulty coping in this study, though it is notable that parents who received more functions of service coordination noted increased satisfaction with family quality of life (Lehman, 1996).

Parents did express needs for respite services, transition services, services for young adults, service coordination, financial assistance for health services, and support for relinquishing custody. Further, they recommended increased flexibility and service coordination as key components to improve mental health service in Oregon (Lehman, 1996). A limitation of this study is that it was completed in Oregon, and, as is evident in the geographic disparities in mental health services noted by Sturm, Ringel, & Andreyeva (2003), the results do not necessarily generalize to Michigan.

Again, though generalizability of the individual studies identified regarding pediatric mental health services is limited, there are some notable commonalities in service concerns and needs illuminated by caregivers. Financial issues pertaining to access and use of pediatric mental health services were noted both by Starr, Campbell, & Herrick's (2002), and by Lehman (1996). The need for service coordination and flexibility noted by Lehman (1996) also related to caregivers' expression of positive characteristics of professionals and services including promptness and convenience (Salmon, Hook, & Hayward, 2003). As with both adult mental health and inpatient mental health studies, emotional support was again identified as a valued aspect of service, including listening and empathy (Arborelius & Bremberg, 2003; Salmon, Hook, & Hayward, 2003). Finally, it appears that previous use of mental health services (Starr, Campbell, & Herrick, 2002; Chavira, et al, 2003) and being well-informed regarding treatments (Chavira, et al 2003; Arborelius & Bremberg, 2003; Lehman 1996) increased the likelihood of service use and satisfaction.

Throughout the literature, recommendations are made regarding the need for further research into the accessibility and quality of mental health services, both for identification of barriers and methods by which improvements can occur (Chun-Chung Chow, Jaffee, & Snowden, 2003; Sturm, Ringel, & Andreyeva, 2003; Walders, et al, 2003; Kosloski, et al, 2002; Starr, Campbell, & Herrick, 2002; Chavira, et al, 2003). The caregiver perspective was acknowledged as a valuable tool in the development and refinement of services to better meet needs in the community identified through such research. The current study sought to develop and pilot a tool by which caregivers' perceptions of services could be explored.

CHAPTER III

METHODOLOGY

Research Design

The ultimate purpose of this study was to develop a survey tool to explore caregivers' perceptions of the accessibility and quality of services available in the community for children with mental health diagnoses and to then pilot that survey. A study specific survey was designed to collect information from caregivers regarding their experiences with mental health services available for their children. Subjects were asked to report on how they obtained services and their satisfaction with services received. Additionally, they were asked to provide information regarding qualities and characteristics of services and professionals they felt impacted the accessibility and quality of those services. The survey, "Service Accessibility and Quality", is included in Appendix A.

The Survey Instrument

A survey was developed specifically for this study to explore caregivers' perceptions of mental health services available in the community for children with mental health diagnoses. Initial development of the survey involved brainstorming quantitative and qualitative questions that fit into the three categories of demographics, accessibility, and quality. The questions were then refined to eliminate identifying characteristics, redundancy, or misleading terminology. Next, the survey was given to two caregivers of a child with developmental disabilities to determine readability, relevance of survey to human services from the perspective of caregivers, and approximate time for completing the survey. Following this review, the survey was revised minimally for improved readability and relevance.

The survey was then distributed to professionals who work with individuals with mental health for content analysis and other professionals who have completed survey

research for both content and form analysis. Following this analysis, content and form changes were made to the survey for further improved readability and relevance, and the survey was once again reviewed by professionals in the field of mental health and those who have completed survey research for final modifications.

HSIRB Application

Due to the involvement of individuals in the research and the possibility of risk for the participants, the project was submitted to the Human Subjects Institutional Review Board at Western Michigan University for an expedited review. Risks and benefits of the study were ascertained, an anonymous survey consent form was developed, and scripts to be used at meetings, online, and in mailings (Appendix B) were composed to invite individuals to participate in the research. Protective actions were also determined to minimize any negative impact on caregivers and/or their children due to participation in the survey, and measures were outlined to maintain confidentiality of all data. Letters of approval from the human subjects institutional review board are included in Appendix C.

Selection of Subjects

Following consultation with professionals in the field of mental health and advocacy organizations, it was determined that parents could best be reached through support groups provided through various organizations. Three organizations – The Michigan Association for Children with Emotional Disorders (MAC ED), Advocacy Services for Kids (ASK), and The Association for Children's Mental Health (ACMH) – were selected in the state of Michigan to contact regarding distribution of the surveys to their participants following approval by the Human Subjects Institutional Review Board.

Initial contact was established with MAC ED, and they expressed interest in participation in the project. The HSIRB approved survey was sent to MAC ED for review prior to agreement to participate. Following this contact, it was very difficulty to

get a hold of the MAC ED representative, and the student researcher was unable to send further surveys to be distributed without approval from the representative.

ASK was a former branch of MAC ED in the Kalamazoo area, and administrators showed an interest in participating in the distribution of the survey at their meetings. A copy of the HSIRB approved survey was sent to the association for review, and they agreed to participate following the transition in administration that was occurring. Following the transition and the approval of slight changes to the research format, the student researcher attended one of their monthly support group meetings to invite individual's to participate in the research. Survey packets were passed around to the caregivers, and 12 packets were taken by potential subjects.

The state office of ACMH was contacted regarding their participation in the survey, and a representative for that area agreed to distribute surveys at her meetings. Support group leaders were then contacted in the various regions in which ACMH conducted their support groups to increase distribution of surveys and attempt to obtain information from various regions throughout the state. In total, 95 surveys were sent to ACMH support group leaders for distribution.

Mid-research Procedural Modifications

Following the passing of the deadline to return surveys, a lack of response prompted re-evaluation of the research process. Support group leaders from ACMH and ASK were asked for their opinions on aspects of the research that may have limited participation of caregivers. A number of leaders identified the deadline as a limiting factor, stating that it may have been too short a time. Additionally, multiple group leaders noted that the length of the survey and the writing demands might be overwhelming for some caregivers. When asked if they felt that having the option to complete the survey through a phone interview would increase participation, leaders felt it might.

HSIRB modifications were made to include a new consent form and script for phone interview participation and to extend the postmark deadline. Support group leaders were notified of these changes and were asked to notify possible participants of

these options. They were also asked to contact the student researcher with any questions or requests for further packets for distribution. In addition to the phone interview option, potential participants at ASK (the support group local to the student researcher) were given the opportunity to participate in a focus group for a round table discussion of the questions in the survey to gather further qualitative data. Copies of forms and procedures used regarding phone interviews and focus groups can be found in appendix D and E, respectively.

The changes to the research process yielded the return of three surveys and one person expressed interest in participation in a focus group. The student researcher left a voice mail message for the individual interested in focus group participation to offer the option of a phone interview in place of the focus group due to limited interest. The potential participant did not respond to the voice mail message, so analysis was based on the three paper surveys completed.

Instrumentation

The survey consisted of 24 questions in three sections. The sections were demographics (ten questions), service accessibility (six questions), and service quality (eight questions). Questions were a mix of Likert-scale style questions and open-ended qualitative questions. This survey was used as the basis for the phone interview script and as an outline of topics for discussion in potential focus groups.

Data Collection and Analysis of Results

Returned surveys were analyzed using thematic analysis. Themes were identified and coded by student researcher. The principle investigator then reviewed these themes for agreement in categorization, and themes were further revised, yielding five themes: (1) bureaucratic hassles and getting the runaround, (2) closed doors, (3) support networks, (4) workers' aptitudes and ineptitudes, and (5) therapeutic relationships.

CHAPTER IV

RESULTS

Population Demographics/General Information

Three surveys of the original 107 provided to support group leaders for distribution were returned, yielding a response rate of 2.8%. The characteristics of the respondents are shown in Table 1.

Of the three respondents, two identified one child receiving mental health services and one identified two children receiving mental health services. The children were 12, 12, 17, and 18, and both 12-year-old were males while the 17- and 18- year olds were females. Community mental health (CMH) services were initiated between the ages of eleven and fifteen, and one respondent (18-year-old female) was no longer receiving community mental health services.

Current and past CMH service utilized included case management, Residential Opportunities Incorporated (ROI – residential and support services), FACT (FACT – comprehensive home and community based intervention), Children's Trauma Assessment Center (CTAC – an intensive transdiciplinary team assessment), individual and family therapy, respite services, psychiatry, mentors, and activity groups. Non-CMH services utilized included hospitalization, private therapy, school services, CUD, private psychiatry, ROI, and YWCA mentor program.

The two respondents with one child receiving CMH services indicated having one other child (both teenagers) in the home while the respondent with two children receiving CMH services did not have any other children. All three respondents were mothers, two biological and one adoptive, who fell in the 44- to 64-year-old age range. They all indicated participation in support groups ranging from occasional attendance to regular attendance in addition to organizing events. All three mothers indicated participation in Advocacy Services for Kids (ASK). In addition, one mother indicated participation in Children and Adults with Attention Deficit-Hyperactivity Disorder (CHADD), and

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another mother noted participation in Kalamazoo Regional Educational Service Agency (KRESA) events and other special seminars for support.

Table 1

General Characteristics of Respondents

	Case 1	Case 2	Case 3
Child's Age	12	17 and 12	18
Child's Gender	Male	Female and male	Female
Child's Diagnosis	PTSD, Mood NOS, ADHD combined, mixed language	Bipolar, OCD, and ODD (F); ADHD, depression, FAS (M)	Bipolar, anxiety
Starting CMH Age	11	15 and 11	12 (no longer receiving)
CMH County	Kalamazoo	*Missing*	*Missing*
CMH Services	Case management	FACT, individual and family therapy	None
Past CMH Services	FACT, respite ("went once, refused all other dates, stated it smelled bad there, kids mean…")	CMH, CTAC, psychiatrist	Case manager, mentor, activity groups
Past Other Services	Hospitalized, private therapy, school speech therapy, ROI	School special ed (IEP), private therapy, CUD, private psychiatrist for meds, inpatient hospitalization	Hospitalization, partial hospitalization, private therapy, IEP at school, mentor with YWCA
Other Children (age)	15 y/o	Only the two receiving CMH services	15 y/o
Relationship to Child	Biological mother	Adoptive mother	Biological mother
Caregiver's Age	44-64	44-64	44-64
Support Group Participation	Occasional attendance	Regular attendance	Regular attendance and organization of events
Which Support Groups	ASK, KRESA events, special seminars	ASK, CHADD	ASK

All three respondents identified social workers and support groups, specifically ASK, as resources for information regarding available services and as referral sources. In addition, two of the mothers noted that they had received information about mental health services from a psychologist or psychiatrist (see Table 2).

Table 2

Caregiver Identified Referral Sources

	Case 1	Case 2	Case 3
Referral Source	Social worker, ASK, and ASK newsletter	Psychiatrist/Psychologist, social worker, MACED/ASK/CHADD groups and newsletters	Social Worker, psychologist, support group (ASK)

When asked to identify the ease of accessing CMH services on a Likert-scale, the two mothers whose children are currently receiving CMH services identified the process as "very difficult" while the mother whose child is no longer receiving CMH services identified the process as "somewhat difficult". When asked to identify the ease of accessing non-CMH services within the community on a Likert-scale, one mother identified the process as "very difficult" and the other two mothers identified the process as "somewhat difficult". The results are shown Table 3.

Table 3

Ease of Service Accessibility

	Case 1	Case 2	Case 3
CMH Services	Very Difficult	Very Difficult	Somewhat Difficult
Non-CMH Services	Very Difficult	Somewhat Difficult	Somewhat Difficult

When asked to identify overall satisfaction with CMH services on a Likert-scale, one mother was "very dissatisfied" and the other was "somewhat satisfied". The child of the third respondent was no longer receiving CMH services. When asked to identify overall satisfaction with non-CMH services on a Likert-scale, two mothers reported being "very satisfied" while the third mother was "somewhat satisfied. The results are shown in Table 4.

Table 4

Overall Satisfaction with Services

	Case 1	Case 2	Case 3
CMH Services	Very Dissatisfied	Somewhat Satisfied	N/A
Non-CMH Services	Very Satisfied	Somewhat Satisfied	Very Satisfied

Caregivers were then asked to rate their satisfaction with various departments of service organizations on a Likert-scale. The results are shown in Table 5. Finally, caregivers were asked to rate the importance of various characteristics of service on a Likert-scale. The results are shown in Table 6.

Table 5

Satisfaction with Services – Department Breakdown

	Case 1	Case 2 (marked based on FACT services)	Case 3
Administrative Staff	Very dissatisfied	Very Satisfied	N/A
Diagnostic Team	Missing	N/A	Very Satisfied (private therapist)
Case Management	Very dissatisfied	Very Satisfied	Somewhat satisfied (when they had it)
Reception Staff	Somewhat dissatisfied	Very Satisfied/ Somewhat Satisfied	N/A

Table 5 – Continued

	Case 1	**Case 2 (marked based on FACT services)**	**Case 3**
Developmental/Therapy Services	Records reflect receipt though he never actually received	Social Work – somewhat satisfied	N/A
Group Activities	N/A (didn't hear about them)	Very Satisfied/Somewhat Satisfied	Somewhat dissatisfied (when they had them)
Recreational Activities	N/A (didn't hear about them)	Somewhat Satisfied	N/A
Work/Vocational Training Services	N/A	N/A	N/A
In-Home Services	(ROI) – Very Satisfied	Somewhat satisfied	N/A
Other	CTAC – Very satisfied	ROI – Somewhat satisfied	
Other		CTAC – very satisfied	

Table 6

Importance of Service Characteristics

	Case 1	Case 2	Case 3
Location of Services	Moderate Importance	Moderate Importance	Minor Importance
Time of Services	Moderate Importance	Major Importance	Moderate Importance
Accessibility of Services	Major Importance	Moderate Importance	Moderate Importance
Other Participants in Services	Major Importance	Major Importance	N/A
Content of Services	Major Importance	*Missing*	Major Importance
Practitioners	Major Importance	Major Importance	*Missing*

In all three cases, mothers consistently commented on the various obstacles they encountered in accessing mental health services for their children. The lengthy intake process was one of the hassles caregivers identified in their discussion of service accessibility. One mother stated, "The paperwork takes much time" and "Families are in major crisis before anything is acted upon" while another mother described the first steps of the intake process: "Went to access center, had 1-2 hour interview. Waited three months. Had second interview." Once services were initiated, one mother still experienced long waits between contacts regarding service. She noted, "Signed up for CM [case management] services on 6/5/05…case worker was to see my son twice a month and never did, 1st call to me to see him was 08/04/05".

Caregivers also expressed frustration with the amount of paper work involved in community mental health services. One mother said, "Paperwork overwhelming with CMH" and "Paperwork takes too much time – obtaining services – such as residential difficult – seems to take too long – too many 'hoops'". Additionally, financial difficulties were noted by mothers: "Believed since [son] was getting worse would need long term respite which I could not afford, $13,000 out of pocket medical expenses 2004 alone for two sons" and "Got case manager @ 2 hours of monthly service. Payments were $550/month…$275/hr for service seemed waaay too high."

Finally, caregivers commented on a lack of information regarding services available and consistently being referred to other sources for answers to their questions. This theme was especially notable in case one. This mother stated, "Access center – intake person does not tell you about the services that are available…after learning through others what other services are available, usually don't know and are referred to one person (upper management)". She also noted a time when a worker's "failure to know CMH policies…resulted in my attendance of three tribunal hearings since CMH personnel did not know the St. of MI vs. KCMH has a different grid…"

Caregivers identified situations in which they felt unable to find the right place for their child due to denial of services. A mother noted, "Got case manager @ 2 hours of monthly service…received reduction in payment for one month, then we were told our daughter was 'fine now and no longer needed assistance'". The other caregivers spoke of the fight to obtain services for which their children were qualified. One mother has had to file two recipients' rights claims so far. Another mother described getting residential treatment for her daughter:

> *Residential treatment 2003 – much needed, but CMH and caseworker were not convinced – worked with other parents and the MAC ED support group parents and staff – outside (CMH) therapists and CTAC to obtain residential treatment.*

The same mother noted that her "daughter [is] unstable – needs residential – hopefully CMH census committee will 'vote' for this."

Other times finding the right place was a struggle because caregivers did not know where to go next for services, which was the case for the mother who said:

> *My son is not making much progress – I don't know if it is*
> *his therapist/caseworker from FACT – should I continue to*
> *search for a therapist [who] will reach him – [stick] with*
> *him or is he not ready to work with any therapist?*

Another mother noted that she "could not find appropriate school placement. She [daughter] quit high school, middle school was a nightmare". Finally, one mother noted that finding the right place was also hard due to the limited resources available for children: "I realize mental health service is under funded…There [are] very few options for mentally ill children – long waits for residential services."

Support Networks

All three mothers identified various outside supports they sought out for multiple purposes. Supports included private therapists, professionals outside of the community

mental health system, and support groups. At times, the supports provided caregivers with information about services from which their children may benefit or with advocacy assistance in obtaining services. When identifying a support, one mother said "my private therapist as she had worked in the system" and another stated "MAC ED – now ASK – support groups – advocates from this group and parents that have been in the CMH system. CTAC also was instrumental in helping my children – and my therapist played a key part in helping get services". The third mother noted, "ASK has been excellent support, both in groups and also having advocates assist us at many school meetings." These supports also offered emotional support for the caregivers and their families. As one mother stated, "Our best support has been our private therapist. She has been totally incredible and available and knows good connections" and "Our therapist is incredible. I feel she has saved daughter's life and vastly improved our family's functioning".

Workers' Aptitudes and Ineptitudes

Caregivers noted clinical ineptitudes they encountered as well as clinical abilities either of professionals with whom they had worked or that they would like to see in future professionals with whom they will work. Characteristics were often noted in dichotomies. For example, one caregiver noted that "...had FACT and the errors in my son's records are too many to count – left FACT team..." and later identified "failure to report document records accurately" as a negative professional characteristic while "documents ACCURATELY" was listed as a positive professional characteristic. Another mother, when describing positive characteristics of a professional with whom she worked stated that she "understands the seriousness of my daughter's illness" and when describing negative characteristics of a different professional said, "This person did not understand my child's illness".

Additional concerns caregivers had with clinicians skills included giving "pat solutions", not knowing what to do in times of crisis, and lacking experience. On the flip side, additional positive clinical skills caregivers noted in professionals with whom they had worked included being knowledgeable, prepared, and creative. Other skills they

would hope for professionals to have included being "well-educated on the latest research" and being able to "think 'outside the box'".

Therapeutic Relationships

Beyond clinical skills, caregivers also had expectations for relationship-based interactions with professionals. Qualities they appreciated in therapeutic relationships included communicating well with families and team members, incorporating the needs of families into treatment, being prompt and accessible, maintaining a non-judgmental and supportive atmosphere, and demonstrating empathy. One mother spoke of a professional with whom she had worked, saying she "Goes out of her way to keep in contact…in frequent contact with my family…works well with all involved…"

Qualities that were perceived as negative in therapeutic relationships included lack of rapport development, failure to follow through, lack of communication with families and/or other team members, not understanding families' needs, and blaming caregivers. One mother noted, "…a family therapist with FACT TEAM in 4 months never developed relationship with kids…" Another mother commented that the "Access interview was painful – I was made to feel like a bad person."

CHAPTER V

DISCUSSION AND CONCLUSIONS

Summary of Results

When compared to current literature regarding mental health accessibility and quality, this study revealed many commonalities regarding limits to accessibility, needs for connections and support, and characteristics of professionals and services that are considered to impact treatment. In addition, in spite of the small number of participants, the study provided important, rich descriptions of community mental health services that expand on previously reported themes, and warrant further consideration and exploration.

The Accessibility Challenge

Whether finding their way through the tangled web of bureaucracy, seeking out information, or seeking out the services that will truly serve their children, caregivers are confronted with accessibility challenges. This was evident in the comments of caregivers in this study and is consistent with previous research. Some of the most notable barriers indicated by caregivers in this study were the lengthy process involved in obtaining services, the paucity of pediatric mental health services, and financial concerns and limitations.

Walders, et al (2003) indicated in their study that barriers to mental health services included difficulty or delay in getting an appointment, the lack of availability of pediatric specialists, and specialist limits related to funding. Tryssenaar, et al (2002) also noted concerns of family members including minimal service availability and monetary issues, and Scharer's (2002) study illuminated the need for improved access to community services due to parents' frustrations with both the availability of and accessibility to services for their children. Starr, Campbell, & Herrick (2002) identified similar concerns regarding financial limitations impacting receipt of mental health care services, and they noted caregivers' dissatisfaction with the mental health services

available for children. Finally, these concerns are consistent with Lehman's (1996) results, which indicated parents desire for financial assistance for mental health services and additional services to better meet children's needs.

Caregivers in this study also indicated great difficulty obtaining appropriate and complete information regarding services available and organizational policies regarding service access and use, a factor that can severely limit service use. In reviewing the literature, it is notable that other studies have found a similar trend in which caregivers feel as though they are not as informed as is necessary or desired. Pejlert (2001) noted parents struggle in obtaining and understanding information presented, which may indicate that when information is presented, it may not be in a format that is understandable to the caregiver. Jubb and Shanley (2002) also found that caregivers were concerned about the completeness, or lack thereof, of information with which they were provided while Arborelius & Bremberg (2003) discovered that mothers appreciated the provision of clear answers and well-explained information. Parents in Scharer's (2002) study noted a need for information in a variety of areas, including the availability of community services, which they felt they had been left to find out about independently, though they may not have been aware of the appropriate questions to obtain necessary information.

Making Connections, Building Support

Through the struggles of obtaining services, previous literature and the current study indicate that caregivers seek out supports beyond institutionalized/public organizations, both to better cope with the process(es) and to advocate in order to facilitate access to said services. Caregivers in this study identified supports that ranged from private professionals (doctors, therapists, and psychiatrists) to support group advocates to fellow parents. Literature suggests other caregivers utilize similar supports.

Nurses were identified as filling the advocacy role for the individuals in Adam, Tilley, & Pollock's (2003) study. Pejlert (2001) and Scharer (2002) both noted the importance of support groups and parents who had been through similar experiences for caregivers of individuals with mental health diagnoses.

Similar to Adam, Tilley, and Pollock's (2003) findings regarding the importance of relationship-based skills in the provision of mental health services, caregivers in this study reported many qualities related to rapport and professionalism as being valuable service and professional traits. They also noted the absence of these traits as being negative characteristics of services and professionals. Relationship-based skills (stated in the positive) identified as valuable through this study included maintenance of a supportive, non-judgmental relationship; demonstration of empathy; incorporating the family and their needs; rapport building; good communication; and promptness and accessibility.

Adam, Tilley, and Pollock (2003) identified clients' needs to not be judged by mental health professionals, while the need for empathy, understanding, and value was seen in Puotiniemi, Kyngas, & Nikkonens's (2002) study on the resources of parents with children in psychiatric inpatient care. Arborelius & Bremberg also found that mothers had a need for positive role support, and Salmon, Hook, & Hayward identified a similar need for empathy in the provision of services. The importance of family-focused intervention was noted in the literature, as was also the case in this study, predominantly as a valued characteristic of services that caregivers did not feel was present. Tryssenaar, et al (2002) identified family members' concerns that there was s decreased acknowledgement of family members roles, while parents in Pejlert's (2001) study noted difficulty having their suggestions heard. In Jubb and Shanley's (2002) study, very few families felt involved in the care of their family member, parent's in Puotiniemi, Kyngas, & Nikkonen's (2002) study also indicated a need to be collaborator's in their children's care, in addition to a desire for open communication with healthcare personnel.

The desirable clinical skills identified by caregivers in this study included the need for knowledgeable, prepared, and creative professionals for the development of treatment techniques that were appropriate. Consistent with the needs expressed by the mothers in this study, parents in Puotiniemi, Kyngas, & Nikkonen's (2002) study noted the need for practical recommendations that could be implemented in the upbringing and treatment of their children. Finally, mother's in Salmon, Hook, and Hayward's (2003)

study identified frustration with professionals offering only ideas they had tried previously, which would suggest a need for other knowledgeable, creative solutions to better address their needs and those of their children similar to the need expressed by mothers in this current study.

Limitations of the Current Study

The intention of this study was to explore caregivers' perceptions of the accessibility and quality of mental health services available in the community for children with mental health diagnoses throughout the state of Michigan. The limited response to the survey did not eliminate the exploratory component but did limit the study to the Kalamazoo, Michigan area, creating a pilot study rather than the full study that was initially intended. Being a pilot study with a low response rate confined to a small geographic area limits the generalizability of the results, though they can still serve as a springboard for further research into this topic.

Regarding the limited response, several explanations may account for the 2.8% rate. First of all, for purposes of confidentiality as well as time and distance limitations, support group leaders were asked to invite members to participate and distribute surveys at their groups. Surveys were sent based on a generous estimate of the number of individuals who would be participating in the group, and so it is possible that all surveys were not distributed, in which case the response rate would be higher. Additionally, the returned surveys all came from the support group at which the student researcher personally invited individuals to participate by reading the invitation that was to be read by support group leaders in the other locations. This personal contact may have encouraged participation, indicating that similar contact may be beneficial in future research. By being present to read the invitation and respond to questions, the student researcher also eliminated the "middle-man" and some of the potential for miscommunication or misinformation regarding the survey and the research, which may have contributed to the increased response rate for this particular support group (approximately 25%). Finally, some support group members had recently participated in

another research study, which may have reduced the likelihood of participation in another study that could take up valuable time they did not have to spare.

Another limitation of this study is that participants were recruited through support groups. Participation in a support group may increase access to services due to the advocacy and support provided in addition to other commonalities that may exist among support group participants that are not true to the general population of caregivers of children with mental health diagnoses. Additionally, when relying on caregiver report, as one must do in a study of caregivers' perceptions, there is the potential that caregivers who have been in extreme situations, especially negative extremes, will be more likely to participate in the study. That said, if the goal is to ultimately address unmet needs within the system, that would include even, and maybe most of all, extremely negative experiences.

Clinical Implications

Certainly limits to the generalizability of this study exist and have been noted. Yet, even as needed further research is completed in this area, practitioners would be wise to take into consideration the findings of this, and many previous studies, indicating that there are, in fact, limits to accessibility of mental health services for children within the community. Additionally, caregivers have noted concerns with quality of services in both this study and others. While the future research is necessary to better identify limits to accessibility and ways in which they can be remediated, some of the caregivers concerns regarding quality can be addressed more simply. Most specifically, individual practitioners can hone rapport development, communication, and relationship-based skills in an attempt to better reach those with whom we work.

Furthermore, previous studies, in addition to the present study, identify the importance of support and advocacy for caregivers of children with mental health diagnoses. Practitioners can assist caregivers in connecting with these supports simply by providing information regarding local support groups and encouraging participation.

The rich information provided from the responses of these caregivers' indicates that caregivers offer a wealth of useful insight that should be taken into account. Replication of this study with a larger sample is recommended to explore perceptions throughout the state of Michigan to see if similar themes arise, as well as obtaining further data to look at the effect various demographic characteristics may have on perceptions of service accessibility and quality. The study could also be replicated on a larger scale in other states throughout the country.

It is also recommended that a tool be developed and utilized to explore children's perceptions of the services in which they participate. Though children may not be familiar with the bureaucracy and accessibility issues, they may have valuable insight into qualities of services to which and professionals with whom they feel most connected, comfortable, and valued. A child's satisfaction with services may impact their willingness to participate, which in turn may impact the outcomes of such services.

Conclusions

This pilot study sought to explore caregivers' perceptions of the quality and accessibility of services available in the community for children with mental health diagnoses in Michigan. While the study did not yield the desired response rate nor representation of the entire state as was initially planned, those surveys that were returned contained rich, informative content leading to the development of five themes. Those five themes, (1) bureaucratic hassles and getting the runaround; (2) closed doors; (3) support networks; (4) workers' aptitudes and ineptitudes; and (5) therapeutic relationships, emerged from the data for an initial description of caregivers' perceptions consistent with previous studies of mental health services, which can then be refined through further research.

The need to continue research into mental health services for children is strong, as consistent disparities in use and limits to accessibility have been noted. One mission of mental health services is to promote the development of children into healthy, productive

members of society. In order to do that, we must continue to strive to offer more quality, accessible services. In addressing the needs of these children, we are addressing the future and the impact these children may have.

Appendix A

Service Accessibility and Quality Survey

Western Michigan University
Department of Occupational Therapy
Principle Investigator: Dr. Ben Atchison
Student Investigator: Karin Brems

You are invited to participate in a research project entitled "Caregivers' perception of services available in the community for children with mental health diagnoses" designed to learn about community mental health services from the caregivers' point of view. This study is being conducted by Dr. Ben Atchison and Karin Brems from Western Michigan University, Department of Occupational Therapy. This research is being conducted as part of the thesis requirements for Karin Brems.

The survey is comprised of 12 questions regarding non-identifying characteristics of your child and the services he/she is receiving, 6 multiple choice and open ended questions about the accessibility of your child's services, and 8 multiple choice and open ended questions about the quality of your child's services. The survey will take approximately 25 minutes to complete. The survey is intended to be completely anonymous, so you will not put your name anywhere on the survey. You may choose to not answer a question and simply leave it blank. You may also choose not to participate in the study.

One potential risk of participating in this study is that talking about the services your child receives and the process of obtaining those services may be emotional for you. If you take a survey, you may choose not to continue filling it out at any time, or you may choose not to return the survey.

By filling out this survey, you may help health professionals gain a better understanding of the needs of your child and family as well as other children and families receiving community mental health services. This may help these professionals provide services that are more directed toward the needs of consumers.

Returning the survey indicates your consent for use of the answers you supply. If you have any questions, you may contact Dr. Ben Atchison at 269-387-7270, Karin Brems at 269-226-8707, the Human Subjects Institutional Review Board at 269-387-8293, or the vice president for research at 269-387-8298.

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board as indicated by the stamped date and signature of the board chair in the upper right corner. You should not participate in this project if the stamped date is more than one year old.

Western Michigan University
Department of Occupational Therapy
Principle Investigator: Dr. Ben Atchison
Student Investigator: Karin Brems

You are invited to participate in a research project entitled "Caregivers' perception of services available in the community for children with mental health diagnoses" designed to learn about community mental health services from the caregivers' point of view. This study is being conducted by Dr. Ben Atchison and Karin Brems from Western Michigan University, Department of Occupational Therapy. This research is being conducted as part of the thesis requirements for Karin Brems.

The survey is comprised of 12 questions regarding non-identifying characteristics of your child and the services he/she is receiving, 6 multiple choice and open ended questions about the accessibility of your child's services, and 8 multiple choice and open ended questions about the quality of your child's services. The survey will take approximately 25 minutes to complete. The survey is intended to be completely anonymous, so you will not put your name anywhere on the survey. You may choose to not answer a question and simply leave it blank. You may also choose not to participate in the study.

One potential risk of participating in this study is that talking about the services your child receives and the process of obtaining those services may be emotional for you. If you take a survey, you may choose not to continue filling it out at any time, or you may choose not to return the survey.

By filling out this survey, you may help health professionals gain a better understanding of the needs of your child and family as well as other children and families receiving community mental health services. This may help these professionals provide services that are more directed toward the needs of consumers.

Returning the survey indicates your consent for use of the answers you supply. If you have any questions, you may contact Dr. Ben Atchison at 269-387-7270, Karin Brems at 269-226-8707, the Human Subjects Institutional Review Board at 269-387-8293, or the vice president for research at 269-387-8298.

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board as indicated by the stamped date and signature of the board chair in the upper right corner. You should not participate in this project if the stamped date is more than one year old.

Thank you for agreeing to participate in the project entitled "Caregivers' perception of services available in the community for children with mental health diagnoses", designed to learn about community mental health services from the caregivers' point of view. The survey will take approximately 20-25 minutes to complete. The survey is intended to be completely anonymous, so please do not put your name anywhere on the survey. You may choose to not answer a question and simply leave it blank. If you have any questions about the survey or project, please contact Karin Brems at 269-226-8707 or Dr. Ben Atchison at 269-387-7270. Please return completed surveys in the enclosed self-addressed, stamped envelope, postmarked no later than Monday, May 16, 2005.

Demographic Information

1. What is your child's birth date (mo/yr), (please list birthdates of all children receiving services through community mental health)_____

2. What is the gender of your child?   *Male*   *Female*

3. What diagnosis or diagnoses has your child been given?
   _____

4. Does your child get services through community mental health?
   a. If yes, how old was your child when he/she first got a service through community mental health?
   _____
   _____

   b. If yes, through which community mental health system of Michigan is your child receiving services?
   _____
   _____

   c. If yes, what community mental health services is your child currently receiving?
   _____
   _____

5. Has your child gotten community mental health services in the past?
   a. If yes, what additional community mental health services has your child received in the past?
   _____
   _____

6. What additional community services (i.e. school services, hospital services, private therapy services) has your child received?
   _____
   _____

7. How many other children do you have and what are their ages?

   _____

   _____

8. What is your relationship to your child? (circle one)
   biological mother   adoptive mother foster mother
   biological father   adoptive father foster father
   *other (please identify)*_____

9. Into which age category do you fall?
   Under 18   19-25   26-34   35-43   44-64   65+

10. Do you participate in a support group?   *Yes   No*
    a. If yes, how often? (check one)
       ___*I regularly attend meetings and take part in organizing events.*
       ___*I regularly attend meetings and events.*
       ___*I regularly attend only meetings.*
       ___*I regularly attend only events.*
       ___*I attend meetings or events occasionally.*

    b. If yes, with which support group(s) do you participate?

       _____

       _____

       _____

Accessibility

1. How did you learn about community services for your child (or who told you about them)? (please circle all that apply)

   Health Professional (please circle type of professional)

   Pediatrician   *Psychiatrist/Psychologist*   *Social Worker*

   Occupational/Physical Therapist   *Speech Language Pathologist*

   Other (please identify)_____

   Support group (please identify) _____

   Newsletter (please identify) _____

   Friend/Relative

   Other (please identify) _____

2. Overall, how easy was it to get community services for your child (please circle one)?

   a. From CMH (community mental health)

   Very Easy   Somewhat Easy   Somewhat Difficult   Very Difficult   N/A

   b. In the community

   Very Easy   Somewhat Easy   Somewhat Difficult   Very Difficult   N/A

3. Please describe the process you went through to get services/a particular service for your child through CMH or in the community.

   _____
   _____
   _____
   _____

4. Tell me about a support (i.e. a person or organization) that may have helped you in getting services through CMH or in the community for your child (describe that support and how they helped you).

   _____
   _____
   _____
   _____

5. Tell me about a problem that may have kept you from getting services for your child through CMH or in the community (What was the problem? Were you able to overcome the problem? If you were able to overcome the problem, how did you do it?).

_____

_____

_____

6. a. Please circle the statement that best describes how you feel about the CMH or community services your child gets…

   My child is getting the services he/she needs from CMH and/or the community.

   My child is not getting the services he/she needs from CMH and/or the community.

   I do not know if my child is getting the services he/she needs from CMH and/or the community.

   My child is getting the right services from CMH and/or the community but would benefit from more services.

   b. If you do not feel your child is getting the services he/she needs from CMH or the community, please list any problems your child may be having that you feel are not being addressed by current services

   _____

   _____

   _____

   c. If you do not feel your child is getting the services he/she needs from CMH or the community, please list services that you feel your child should be getting

   _____

   _____

   _____

Quality

1. Overall, how would you rate your satisfaction with the quality of services your child gets through CMH and/or the community (please circle one)?

   a. Through CMH (please circle one)

Very Satisfied   Somewhat Satisfied   Somewhat Dissatisfied   Very Dissatisfied   N/A

   b. In the community

Very Satisfied   Somewhat Satisfied   Somewhat Dissatisfied   Very Dissatisfied   N/A

2. Please describe a service with which you were very satisfied (please indicate if *CMH* or *non-CMH*).

   _____

   _____

   _____

   _____

   _____

   _____

3. Please describe a service with which you were very dissatisfied (please indicate if *CMH* or *non-CMH*).

   _____

   _____

   _____

   _____

   _____

   _____

4. Please describe the characteristics of a service that might make you dissatisfied.

   _____

   _____

   _____

   _____

   _____

   _____

5. Overall, how would you rate your satisfaction with the quality of services provided by each of the following sections of CMH or service providers in the community? (Please check one, or check N/A for services that do not apply to your child). Comment lines are provided at the   end of the section if you care to write more about any of your satisfaction ratings.

	Very Satisfied	Somewhat Satisfied	Somewhat Dissatisfied	Very Dissatisfied	N/A
Administrative Staff (managers, directors)					
Diagnostic Team					
Case Management					
Reception Staff					
Developmental/Therapy Services (i.e. occupational therapy, speech language pathology, social work, psychology)					
Group Activities					
Recreational Opportunities					
Work/Vocational Training/Services					
In-home Services					
Other (please identify) _____					
Other (please identify) _____					

Comments_____

_____

_____

_____

_____

6. Overall, how important is each of the characteristics listed below in deciding if you are satisfied with the services your child gets from CMH or in the community...

	Major Importance	Moderate Importance	Minor Importance	No Importance	N/A (only for "other participants")
Location of Services					
Time of services					
Accessibility of services (i.e. ease of application and intake process)					
Other participants in services (for group activities)					
Content of services					
Practitioners/Health Professionals/Staff					

7. Please describe the personality and/or professional characteristics of a practitioner or staff member with whom you were very satisfied. (Please do not mention names)

_____

_____

_____

_____

8. Please describe the personality and/or professional characteristics of a practitioner or staff member with whom you were very dissatisfied.

_____

_____

_____

_____

Brems, K. (2004). Service accessibility and quality. Unpublished survey for use in caregiver perception study.

Appendix B

Invitations to Participate in Study

To be read to support groups

I am reading this on behalf of Karin Brems. She is a graduate student in Western Michigan University's post-professional master's program in occupational therapy and an Occupational Therapist for the Southwest Michigan Children's Trauma Assessment Center. She is currently conducting a survey research study entitled "Caregivers' perceptions of services available in the community for children with mental health diagnoses" to gain a better understanding of how caregivers view the services their child/children are receiving in the community. If you are interested in participating in this survey, I have copies available and a self-addressed stamped envelope in which you can return the survey. You may also choose to fill out a sign-up sheet to be contacted for a phone interview. If you are interested in learning more about the survey, please contact Karin at 269-226-8707 or karin.brems@wmich.edu.

To be read by researcher at Kalamazoo Area Support Group

My name is Karin Brems. I am a graduate student in Western Michigan University's post-professional master's program in occupational therapy and an Occupational Therapist for the Southwest Michigan Children's Trauma Assessment Center. I am currently conducting a survey research study in the state of Michigan entitled "Caregivers' perceptions of services available in the community for children with mental health diagnoses" to gain a better understanding of how caregivers view the services their child/children are receiving in the community. If you are interested in participating in the survey, I have copies of the survey and return envelopes. You may also choose to fill out a sign-up sheet to be contacted for a phone interview. In addition, I am interested in information that could come from a group discussion regarding community services. If you are interested in participating in a focus group in the middle of May to voice your perceptions of services, you may choose to fill out a sign-up sheet to be contacted about participation. If you are interested in learning more about the survey or participating in the support group, please contact me at 269-226-8707 or karin.brems@wmich.edu. I will pass around packets that include the survey, sign up forms for the phone interview and the focus group, consent forms, and return envelopes. Please feel free to take one if you are interested or would like more information. Thank you for your time and consideration.

<u>To be printed in the newsletter or in an email</u>

My name is Karin Brems. I am a graduate student in Western Michigan University's post-professional master's program in occupational therapy and an Occupational Therapist for the Southwest Michigan Children's Trauma Assessment Center. I am currently conducting a survey research study in the state of Michigan entitled "Caregivers' perceptions of services available in the community for children with mental health diagnoses" to gain a better understanding of how caregivers view the services their child/children are receiving in the community. If you are interested in participating in the survey, please contact your local branch of MACED/ASK/ACMH for a copy of the survey and a return envelope. You may also choose to fill out a sign-up sheet to be contacted for a phone interview. If you are interested in learning more about the survey, please contact me at 269-226-8707 or karin.brems@wmich.edu.

Appendix C

Protocol Clearance From the Human Subjects Institutional Review Board

WESTERN MICHIGAN UNIVERSITY

Human Subjects Institutional Review Boar

Centennial
1903-2003 Celebration

Date: July 29, 2004

To: Ben Atchison, Principal Investigator
        Karin Brems, Student Investigator

From: Amy Naugle, Ph.D., Interim Chair

Re: HSIRB Project Number 04-07-23

This letter will serve as confirmation that your research project entitled "Caregivers' Perceptions of the Accessibility and Quality of Services available in the Community for Children with Mental Health Diagnoses" has been **approved** under the **exempt** category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may **only** conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: July 29, 2005

Walwood Hall, Kalamazoo, MI 49008-5456
PHONE: (269) 387-8293 FAX: (269) 387-8276

WESTERN MICHIGAN UNIVERSITY

Date: April 20, 2005

To: Ben Atchison, Principal Investigator
Karin Brems, Student Investigator

From: Mary Lagerwey, Ph.D., Chair *Mary Lagerwey*

Re: Changes to HSIRB Project Number: 04-07-23

This letter will serve as confirmation that the changes to your research project "Caregivers' Perceptions of the Accessibility and Quality of Services Available in the Community for Children with Mental Health Diagnoses" requested in your memo dated 4/11/2005 and clarified in your memos dated April 15, 2005 and 4/19/2005 have been approved by the Human Subjects Institutional Review Board.

The conditions and the duration of this approval are specified in the Policies of Western Michigan University.

Please note that you may **only** conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: July 29, 2005

Date: April 20, 2005

To: Ben Atchison, Principal Investigator
        Karin Brems, Student Investigator

From: Mary Lagerwey, Ph.D., Chair   *May Lagy*

Re: Changes to HSIRB Project Number: 04-07-23

This letter will serve as confirmation that the changes to your research project "Caregivers' Perceptions of the Accessibility and Quality of Services Available in the Community for Children with Mental Health Diagnoses" requested in your memo dated 4/11/2005 and clarified in your memos dated April 15, 2005 and 4/19/2005 have been approved by the Human Subjects Institutional Review Board.

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Please note that you may **only** conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: July 29, 2005

Appendix D

Phone Interview Forms

Western Michigan University
Department of Occupational Therapy
Principle Investigator: Dr. Ben Atchison
Student Investigator: Karin Brems

You are invited to participate in a research project entitled "Caregivers' perception of services available in the community for children with mental health diagnoses" designed to learn about community mental health services from the caregivers' point of view. This study is being conducted by Dr. Ben Atchison and Karin Brems from Western Michigan University, Department of Occupational Therapy. This research is being conducted as part of the thesis requirements for Karin Brems.

(Please check the statement that applies to you)

_____ I am not interested in participating in a focus group.

_____ I am interested in being contacted to participate in a focus group.

If you checked the first statement, you may return this sheet to your support group leader or throw it away. If you checked the second statement, please provide the following information...

First name only: _____

Best phone number to contact you: __(_____)_____-_____

Best day(s) of the week to contact you: _____

Best time(s) of the day to contact you: _____

Best day(s) and time(s) to schedule a focus group: _____

My signature below (first name only) indicates that I am willing to be contacted about participating in a focus group. I am aware that I can change my mind and choose not to participate in the focus group when the researcher contacts me.

_____   _____
Signature   Date

Western Michigan University
Department of Occupational Therapy
Principle Investigator: Dr. Ben Atchison
Student Investigator: Karin Brems

You are invited to participate in a research project entitled "Caregivers' perception of services available in the community for children with mental health diagnoses" designed to learn about community mental health services from the caregivers' point of view. This study is being conducted by Dr. Ben Atchison and Karin Brems from Western Michigan University, Department of Occupational Therapy. This research is being conducted as part of the thesis requirements for Karin Brems.

The phone interview is comprised of 12 questions regarding non-identifying characteristics of your child and the services he/she is receiving, 6 multiple choice and open ended questions about the accessibility of your child's services, and 8 multiple choice and open ended questions about the quality of your child's services. The interview will take approximately 25 - 40 minutes to complete. The interview is intended to be completely confidential, so you will not use your last name during the interview, and your name will not be used in any published results. You may choose to not answer a question and simply pass during the interview. You may also choose not to participate in the study.

One potential risk of participating in this study is that talking about the services your child receives and the process of obtaining those services may be emotional for you. If you sign up for a phone interview, you may choose not to continue answering questions at any time, or you may choose not to respond to any questions when the interviewer calls.

By participating in this phone interview, you may help health professionals gain a better understanding of the needs of your child and family as well as other children and families receiving community mental health services. This may help these professionals provide services that are more directed toward the needs of consumers.

Participating in the phone interview indicates your consent for use of the answers you supply. If you have any questions, you may contact Dr. Ben Atchison at 269-387-7270, Karin Brems at 269-226-8707, the Human Subjects Institutional Review Board at 269-387-8293, or the vice president for research at 269-387-8298.

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board as indicated by the stamped date and signature of the board chair in the upper right corner. You should not participate in this project if the stamped date is more than one year old.

Phone Interview Informed Consent Process

1. Potential participants who returned signed sheets to be contacted for a phone interview will be called by the student researcher.

2. If the potential participant is not home and someone else answers the phone, the student researcher will ask if there is a better time to call the potential participant back and will call back later at the recommended time or at another time indicated on the potential participants sign-up sheet. The student researcher will not mention the specific purpose of the phone call.

3. If the potential participant is not home and the student researcher gets no answer or an answering machine, the student researcher will hang up and call back at another time indicated on the potential participant's sign-up sheet. No message will be left regarding the specific purpose of the phone call.

4. If the potential participant is home, the student researcher will continue with the phone interview process by introducing herself and stating her purpose for calling.

"My name is Karin Brems. I am an occupational therapist and a graduate student at Western Michigan University. I received a sheet from (support group/leader name) that you filled out indicating you are interested in participating in a phone interview about services available in the community for children with mental health diagnoses. Are you still interested in participating?"

5. If the potential participant says no, the student researcher will say, *"Thank you for your time. Have a nice day."*

6. If the potential participant says yes, the student researcher will continue with the introductory process.

"I appreciate your willingness to participate. Is now a good time for the phone interview?"

7. If the potential participant says no, the student researcher will ask when a better time would be and then say, *"I look forward to talking to you at that time. Have a nice day."*

8. If the potential participant says yes, the student researcher will continue with the informed consent process.

"When you filled out your sign-up sheet, there was an attached consent document explaining the phone interview. Have you read that document?"

9. If the potential participant says no, the student researcher will let the individual know she is going to read the document to them and will then read the consent document verbatim. The student researcher will then move on to step 10.

10. If the potential participant says yes, the student researcher will ask, *"Do you have any questions regarding the study or the information provided in that document/that was just read to you?"*

11. If the potential participant says no, the student researcher will proceed with step 13.

12. If the potential participant says yes or asks a question, the student researcher will respond to the questions and then proceed to step 13.

13. The student researcher will then ask the potential participant *"Do you still wish to participate in this phone interview?"*

14. If the potential participant says no, the student researcher will say, *"Thank you for your time. Have a nice day."*

15. If the potential participant says yes, the student researcher will say, *"Thank you again for your willingness to participate. If at any time you change your mind about participating, please just let me know. We will begin with the questions now."*

16. The student researcher will then ask the participant the questions detailed in the survey tool developed for this study and will document the participant's responses. If the participant chooses not to answer an individual question, the student researcher will move on to the next question. If at any time the participant chooses to discontinue the interview, the student researcher will say, *"Thank you for your time. Have a nice day."*

17. When the survey is complete, the student researcher will ask, *"Do you have any (more) questions for me?"*

18. If the participant says no, the student researcher will say, *"Thank you for your time. If you have any further questions and wish to contact me, my number is on the consent document. Have a nice day."*

19. If the participant says yes or asks a question, the student researcher will answer the questions and will then say, *"Thank you for your time. If you have any further questions and wish to contact me, my number is on the consent document. Have a nice day."*

Appendix E

Focus Group Forms

Western Michigan University
Department of Occupational Therapy
Principle Investigator: Dr. Ben Atchison
Student Investigator: Karin Brems

You are invited to participate in a research project entitled "Caregivers' perception of services available in the community for children with mental health diagnoses" designed to learn about community mental health services from the caregivers' point of view. This study is being conducted by Dr. Ben Atchison and Karin Brems from Western Michigan University, Department of Occupational Therapy. This research is being conducted as part of the thesis requirements for Karin Brems.

(Please check the statement that applies to you)

_____ I am not interested in participating in a phone interview.

_____ I am interested in being contacted for a phone interview.

If you checked the first statement, you may return this sheet to your support group leader or throw it away. If you checked the second statement, please provide the following information and return this sheet to your support group leader. Keep the attached consent document for your records.

First name only: _____

Best phone number to contact you: __(_____)_____-_____

Best day(s) of the week to contact you: _____

Best time(s) of the day to contact you: _____

My signature below (first name only) indicates that I am willing to be contacted for a phone interview. I have read the attached consent document and am aware that I can change my mind and choose not to participate in the phone interview when the researcher contacts me.

_____
Signature   Date

Western Michigan University
Department of Occupational Therapy
Principle Investigator: Dr. Ben Atchison
Student Investigator: Karin Brems

You are invited to participate in a research project entitled "Caregivers' perception of services available in the community for children with mental health diagnoses" designed to learn about community mental health services from the caregivers' point of view. This study is being conducted by Dr. Ben Atchison and Karin Brems from Western Michigan University, Department of Occupational Therapy. This research is being conducted as part of the thesis requirements for Karin Brems.

The focus group is based on a survey requesting non-identifying characteristics of your child and the services he/she is receiving and information about the accessibility and quality of your child's services. The focus group will take approximately 45 - 60 minutes to complete. The focus group is intended to be confidential, so you will only use first names during the focus group discussion, and no names will be used in published results. The discussion will be audiotaped so the student researcher can record all information provided, but the tape will only be heard by the researchers. You may choose to not answer a question and pass on that question. You may also choose not to participate in the study.

One potential risk of participating in this study is that talking about the services your child receives and the process of obtaining those services may be emotional for you. If you sign up to participate in the focus group, you may choose not to continue participating at any time.

By participating in this focus group, you may help health professionals gain a better understanding of the needs of your child and family as well as other children and families receiving mental health services. This may help these professionals provide services that are more directed toward the needs of consumers.

Your signature below indicates your consent for use of the information you supply during the focus group discussion. If you have any questions, you may contact Dr. Ben Atchison at 269-387-7270, Karin Brems at 269-226-8707, the Human Subjects Institutional Review Board at 269-387-8293, or the vice president for research at 269-387-8298.

_____   _____
Signature   Date

My signature below indicates that I agree not to discuss outside of this focus group any comments made by the other participants.

Signature   Date

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board as indicated by the stamped date and signature of the board chair in the upper right corner. You should not participate in this project if the stamped date is more than one year old.

Focus Group Phone Contact Process

1. Potential participants who returned signed sheets to be contacted to participate in a focus group will be called by the student researcher.

2. If the potential participant is not home and someone else answers the phone, the student researcher will ask if there is a better time to call the potential participant back and will call back later at the recommended time or at another time indicated on the potential participants sign-up sheet. The student researcher will not mention the specific purpose of the phone call.

3. If the potential participant is not home and the student researcher gets no answer or an answering machine, the student researcher will hang up and call back at another time indicated on the potential participant's sign-up sheet. No message will be left regarding the specific purpose of the phone call.

4. If the potential participant is home, the student researcher will continue with the phone interview process by introducing herself and stating her purpose for calling.

"My name is Karin Brems. I am an occupational therapist and a graduate student at Western Michigan University. I received a sheet from Sandy at Advocacy Services for Kids that you filled out indicating you are interested in participating in a focus group about services available in the community for children with mental health diagnoses. Are you still interested in participating?"

5. If the potential participant says no, the student researcher will say, *"Thank you for your time. Have a nice day."*

6. If the potential participant says yes, the student researcher will continue with the introductory process.

"I appreciate your willingness to participate. I have selected the following date and time for the focus group. Is that a date and time that will work for you?"

7. If the potential participant says no, the student researcher will ask, *"Would you be willing to participate in a phone interview instead of the focus group?"* The student researcher will then proceed to the informed consent process detailed for the phone interview.

8. If the potential participant says yes, the student researcher will provide the location of the focus group and ask, *"Do you have any questions about the focus group?"*

9. If the potential participant says no, the student researcher will say, *"Thank you again for your willingness to participate. I look forward to seeing you at*

(location) on (date) at (time). If you have any (more) questions before that time, please feel free to call me, Karin Brems, at 269-226-8707. Have a nice day."

10. If the potential participant says yes or asks a question, the student researcher will say, *"Thank you again for your willingness to participate. I look forward to seeing you at (location) on (date) at (time). If you have any (more) questions before that time, please feel free to call me, Karin Brems, at 269-226-8707. Have a nice day."*

Focus Group Informed Consent Process

1. Focus group consent documents will be given to the participants as they arrive at the focus group as will an information card (as described in the *focus group outline*). Participants will be informed that they will go over the consent document as a group and asked to fill in any information they are comfortable providing on the card.

2. When all participants have arrived and received the consent document, the student researcher will introduce herself.

"My name is Karin Brems. I am an occupational therapist and a graduate student at Western Michigan University. I would like to start by thanking you for taking the time to attend this focus group today. The form I gave you when you came in was a consent document regarding your participation in this focus group. I will read that document aloud now."

3. The focus group consent document will be read verbatim to the participants up to the first signature line. They will then be asked, *"Does anyone have any questions about the study or the information I just read?"*

4. If the participants say yes or ask questions, the student researcher will respond to questions and then proceed.

5. If the participants say no, the student researcher will say, *"If you are still interested in participating in the focus group discussion and understand the consent information, please sign your first name and date the first signature line."*

6. If any participants decide they do not want to participate after reading the consent document, they will have the option of sitting quietly (so long as they complete the second portion of the consent document) or leaving at that time after being thanked for their time and interest.

7. The student researcher will then read the confidentiality clause in the consent document verbatim to the participants. They will then be asked, *"Does anyone have any questions about the information I just read?"*

8. If the participants say yes or ask questions, the student researcher will respond to the questions and then proceed.

9. If the participants say no, the student researcher will say, *"If you agree to the confidentiality clause, please sign your first name and date the second signature line. Everyone in this room needs to agree to the confidentiality clause before we proceed with the group."*

10. Signed consent forms will be collected and participants will be provided with a clean copy of the consent for their records.

11. The student researcher will inform the participants that they will be beginning and will remind participants that, *"If at any time you wish to not answer a particular question, please remember that is your choice. You may also choose to discontinue participation and/or leave at any time if you would like. Does anyone have any further questions before we begin?"*

12. If the participants say yes or ask questions, the student researcher will respond to questions and then proceed.

13. If the participants say no, the student researcher will begin the focus group, following the *focus group outline*.

Focus Group Outline–

1. Introductions–(following the informed consent process) place cards to be filled out and kept in front of individuals for reference–include caregiver first name, child's age, child's diagnosis, caregiver's relationship to child, age (range) of caregiver–response to questions on place card, as with all participation, is optional.
   a. Go around and introduce self by first name
   b. Facilitator to present participants with focus group consent letter
   c. Facilitator to present outline of focus group
   d. Questions prior to starting discussion

2. Service Accessibility
   a. What are your primary resources for information about services available for your child?
   b. Would anyone care to share a story about the process of getting a particular service for his or her child?
   c. Are there particular supports that assist in getting services?
   d. Are there particular problems that keep you from getting services or increase the difficulty?
   e. Do you feel your child is getting the services he/she needs in the community?

3. Service Quality
   a. Would anyone care to describe a service with which they were very satisfied?
   b. Would anyone care to describe a service with which they were very dissatisfied?
   c. What characteristics of a service help you decide if you are satisfied with the service (i.e. location, accessibility, participants, professionals)
   d. Would anyone care to describe the personality and/or professional characteristics of a practitioner or staff member with whom you were very satisfied? (No names)
   e. Would anyone care to describe the personality and/or professional characteristics of a practitioner or staff member with whom you were very dissatisfied? (No names)

4. Closing
   a. Are there any other strengths or areas for improvement you see regarding services that were not covered in previous questions?
   b. Do you have any further questions for me?
   c. Thank you for your participation

Appendix F

Thick Data

THICK DATA

Please describe the process you went through to get services/a particular service for your child through CMH or in the community.

Case 1: Access Center – intake person does not tell you about the services that are available, you are asked what you want and then asked to agree to your request. Upon calling back, or asking those working with you, after learning through others what other services are available, usually don't know and referred to one person (upper management).

Case 2: The process and paperwork takes much time. Paperwork overwhelming with CMH. I first tried adoption subsidy – after months of paperwork – phone calls found that we didn't qualify, then met? contacted CMH to set up intake appointment, then after a few months was assigned a caseworker, also needed to see CMH worker to see what I could afford to pay for services.

Case 3: (This took place 6 yrs ago). Went to Access Center, had 1-2 hour interview. Waited 3 months. Had second interview to determine payment level. Got case manager @ 2 hours monthly service. Payments were $550/month. Appealled and received reduction in payment for 1 month, then we were told our daughter was "fine now + no longer needed assistance." Got private therapist by phoning and waiting about 1 month for first appointment. This therapist helped us to find a good psychiatrist and helped arrange first hospitalization. Never did find any respite services, CMH or private.

Tell me about a support (i.e. a person or organization) that may have helped you in getting services through CMH or in the community for your child (describe that support and how they helped you).

Case 1: My private therapist as she had worked in the system (CPS) (no longer would [with] good reason I suspect). Believed son [name eliminated] was getting worse.

Would need long term respite which I could not afford, $13,000 out of pocket medical expenses for 2004 alone for 2 sons.

Case 2: MACED – now ASK – support group – advocates from this group and parents that have been in the CMH system, CTAC also was instrumental in helping my children – and my therapist played a key part in helping get services.

Case 3: Our best support has been our private therapist. She has been totally incredible and available and knows good connections. ASK has been excellent support, both in the groups and also having advocates assist us at many school meetings.

Tell me about a problem that may have kept you from getting services for your child through CMH or in the community (what was the problem? Were you able to overcome the problem? If you were able to overcome the problem, how did you do it?).

Case 1: Completed intake paperwork 07/04, advised since child was on visitation with other parent, then no meeting could occur until child was available. Then pasturing [?] in setting up meeting when child was back in state and so I would not miss work. Went to meeting with my child who refused to enter the room for the meeting. Intake person asked what was wrong with child (?) and then said OK child does not have to be present.

Case 2: Residential treatment 2003 – much needed, but CMH + caseworker were not convinced – worked with other parents + the MACED support group parents + staff – outside (CMH) therapists + CTAC to obtain residential treatment.

Case 3: Part of problem was child did not like some groups offered by CMH and refused to attend. Also, see accessibility #3 [p. 76, case 3] for description of money issue. $275/hr for service seemed waaay too high.

If you do not feel your child is getting the services he/she needs from CMH or the community, please list any problems your child may be having that you feel are not being addressed by current services

Case 1: Where do I begin: Signed up for CM services on 6/5/05, case worker was to see my son twice a month and never did, 1st call to me to see him was 08/04/05 – First call for PCP occurred 07/24/05. Prior had FACT TEAM and the errors in my son's records are too many to count. Filed two receipt rights complaints [recipient rights?]. Left CMH FACT TEAM. The inexperience with CMH is awful.

Case 2: My son is not making much progress – I don't know if it is his therapist/caseworker from FACT – ~~or perhaps~~ should I continue to search for a therapist that will reach him – click with him or is he not ~~capable of~~ ready to work with any therapist?

Case 3: Could not find appropriate school placement. She [daughter] quit high school. Middle school was a nightmare.

If you do not feel your child is getting the services he/she needs from CMH or the community, please list services that you feel your child should be getting

Case 1: Therapy, to include OT evaluation, explanation why other families receive reimbursement on co-pays (I have insurance + no ability to pay – per CMH financial intake) recreational therapy.

Case 2: Daughter unstable – needs residential – hopefully CMH census committee will "vote" for this.

Case 3: We would have benefited from respite care when she was younger.

Please describe a service with which you were very satisfied (please indicate if CMH or non-CMH).

Case 1: ROI – non-CMH, CTEK [CTAC] – non-CMH, Mobile Crisis – CMH, Dr. Sloane – non-CMH – I am private pay

Case 2: I was extremely satisfied with CTAC, FACT – Children + Family Services – satisfied – good communication with family, frequent contact, meetings, The FACT team has been, overall, a good program – much better than CMH. The team works together and really tries to work with the family. FACT team even made an exception by allowing a therapist from private practice to continue therapy with one child.

Case 3: Our therapist is incredible. I feel she has saved daughter's life and vastly improved our family's functioning.

Please describe a service with which you were very dissatisfied (please indicate if CMH or non-CMH).

Case 1: FACT Program – CMH, Case Mgmt Program – CMH

Case 2: CMH – It was very frustrating working with CMH workers. Before FACT involvement CMH was difficult to work with, very frustrating to obtain services – the process for getting services. I made progress by enlisting outside help from a support group, outside therapists, and CTAC.

Case 3: Girl's group – daughter ran away from it and no one knew what to do. Access interview was painful – I was made to feel like a bad person.

Please describe the characteristics of a service that might make you dissatisfied.

Case 1: Not being honest, no follow through, filling in blanks on authorizations after I signed them, not knowing how to complete paperwork correctly, failure to properly document, failure to know CMH policies which resulted in my attendance of 3 tribunal hearings since CMH personnel did not know the St. of MI. vs. KCMH has a different grid in determining ability to pay for long-term hospitalization. And there is MORE!

Case 2: Paperwork takes too much time – obtaining services – such as residential difficult – seems to take too long – too many "hoops" Families are in major crisis before anything is acted upon. I realize Mental Health Services are under funded in Mich + U.S. (Federal) There is very few options for mentally ill children – long waits for residential services.

Case 3: *No response*

{Overall, how would you rate your satisfaction with the quality of services provided by each of the following sections of CMH or service providers in the community? (Please check on, or check N/A for services that do not apply to your child).}
Comment lines are provided at the end of the section if you care to write more about any of your satisfaction ratings.

Case 1: I've contacted St. of MI. so that when they review files that our file is pulled for review. Needless to say the dept. overseeing CMH was very interested.

Case 2: CMH + therapy service very dissatisfied – FACT very satisfied with most of team – overall satisfied. Think you should have a category "satisfied". Satisfied with FACT admin.

Case 3: *No response*

Please describe the personality and/or professional characteristics of a practitioner or staff member with whom you were very satisfied (Please do not mention names)

Case 1: Knowledge – more than a basic knowledge of social work 101, or better yet did not state something they did not know about, friendly, tone, promptly returns telephone calls, prompt, understands the dynamics of the family when living with a child who is severely disregulated. Documents ACCURATELY.

Case 2: Goes out of her way to keep in contact, knowledgable as a caseworker, in frequent contact with my family, understands the seriousness of my daughter's illness, works well with all involved, she "gets it" Also plans for meetings, prepared, creative in her therapy.

Case 3: Well educated on latest research, non-judgmental, supportive, can think "outside the box", available i.e. easily accessible.

Please describe the personality and/or professional characteristics of a practitioner or staff member with whom you were very dissatisfied.

Case 1: TONE – Never followed thru, a family therapist w/ FACT TEAM in 4 months never developed relationship w/ kids + never had much to say other than confirmation of how difficult it was for family, LACK of experience, failure to know CMH policies, failure to document records accurately.

Case 2: This person did not understand my child's illness, did not keep me informed, set up appointments but cancelled numerous times, ignored repeated requests to involve my other child – who was in crisis Did not seem to under[stand] my families needs didn't seem to have a clue

Case 3: Narrow, judging, doesn't listen, gives pat solutions, doesn't return calls, blaming attitude instead of collaborating.

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