Findings Brief 3

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Family Experience
of the
Mental Health System

Decisions and Responsibilities of Care

The **Family Experience of the Mental Health System** (**FEMHS**) utilized a qualitative, longitudinal approach following thirty families over a period of two years. Families shared their experiences as they sought services, entered treatment, and remained in or terminated services. During those two years, the parents and caregivers who participated in the study were asked in thirteen separate interviews about how and why they made the decisions they made.

Caregivers reported that, from the start, decisions were made that involved the identification of a mental health problem. Families were unsure whether or not their children's behavior, including anger or unacceptable behavior in school, was related to the experiences of growing up, or if it was related to a mental health condition.

Caregivers sought services for their children and continued those services based primarily on a perception that an evaluation/ assessment or intervention was needed for emotional, behavioral, and/or social problems. When seeking services initially, many caregivers accepted the services offered, feeling they had no choice, as well as the opinions and recommendations of professionals concerning their children's needs and how those needs would be best served. Over the course of the study, caregivers took a larger role in making decisions concerning services, wanting

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more information about their children's illnesses. This increase in involvement seemed to correspond with a growing knowledge about their children's problems, the services available, and their rights to services.

Many families had a difficult time deciding whether or not their children would take medication. They were concerned about the side effects and preferred to stop medicating their children for several months to prevent side effects from being too severe. These decisions to change the medication regimen often took place without prior authorization from the clinician.

Caregivers made every effort to make decisions that were in their children's best interests, while attempting to balance the challenges of everyday living. In many cases, decisions were made within the context of other stressful life events, including unemployment, poor health, and troubled relationships. However, while families made decisions about services they believed they and their children needed and sought, they did not typically have control over the services they ultimately received due to a variety of limiting factors, including the limitations of insurance, lack of or limited funds to pay for services, lack of transportation, child's lack of eligibility, employment concerns.

Families made decisions to discontinue services relatively infrequently. These decisions were made for a variety of reasons, including repeated changes in therapists, service duplication or overload, dissatisfaction, and lack of need or benefit. Some reasons that families mentioned — cost of transportation, distance from services, lack of communication from providers and negative experiences with providers or agency staff — are reflected as well in the current literature (Kruzich et al., 2003). The decision to continue services was primarily based on ongoing need and because families perceived that services were beneficial. Families also reported that their intake experience — whether they were treated with respect or not — was pivotal to service continuation.

Out of thirty families, the study had a total of eight Hispanic families. Their experiences with decision-making as they sought services, entered treatment, and remained in or terminated treatment or services and supports varied depending on their country of origin, language proficiency, education, and immigration status and permanency. Issues regarding relocating were a consistent theme for most of the families. Families moved for several reasons. They moved to the United States looking for a better life, moved several times back and forth from their native country or moved within the cities looking for safer neighborhoods. A move usually included a change in service provision. For one family, a move to a safer neighborhood within the same city resulted in the loss of a bilingual worker being assigned to her. Another mother opted to send her children back to her native country since she believed it was easier, faster and less expensive to get services there than waiting for the assessments to be done in the United States.

"They sent him to the school over there, to an alternative school, because he don't respect adults."

"He is behaving better now; I think he is just growing up."

"[He needs] something to work with his attitude…I guess to make him feel better and to forget what happened in the past…because it's in [him] and [he needs to] let it out."
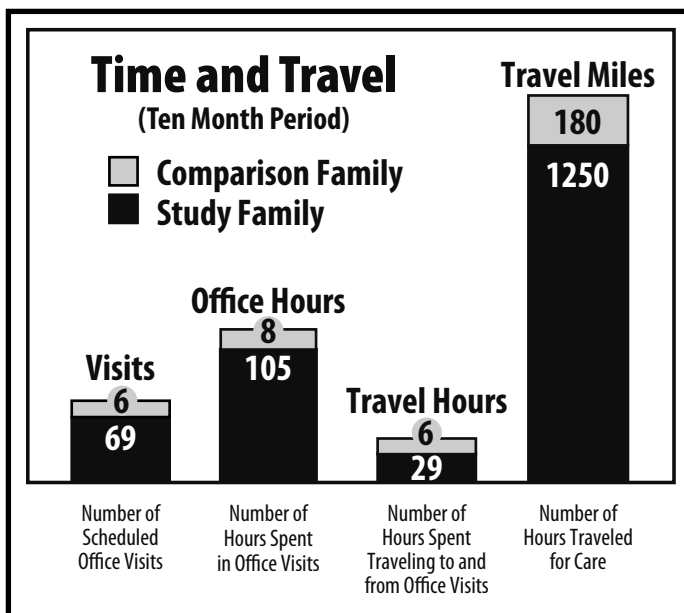
"Her teacher last year wanted to put her in an EMH class. And I refused. I wanted her to have a regular kindergarten curriculum."

"Well, I look at, is it something that's going to benefit her, or is it harming her?"

"The reason I closed them [a therapeutic service] is because her therapist is going to move… so I'm like, 'Okay, do I want another person?'"

One of the key decisions caregivers made was to continue to advocate for the needs and rights of their children. Seeing this as a fundamental part of their responsibility to care for their children, parents and caregivers spent endless hours and made extraordinary efforts to obtain the services they believed were needed and tackled any roadblocks encountered along the way. The drain on their personal resources to continue seeking or remaining in services was significant, especially because many had other children with special needs, personal and other family health problems, financial strain (resulting in bankruptcy for two families), and other co-occurring life events.

The **Time and Travel** graph below illustrates the amount of time one parent spent and the number of miles she drove to keep her child in services. Her experience was typical of most families in the study. Her results are compared over a ten-month period to a parent whose child was not in need of special services

Time and Travel
(Ten Month Period)

☐ **Comparison Family**
■ **Study Family**

Travel Miles
180
1250

Office Hours
8
105

Visits
6
69

Travel Hours
6
29

| Number of Scheduled Office Visits | Number of Hours Spent in Office Visits | Number of Hours Spent Traveling to and from Office Visits | Number of Hours Traveled for Care |

These findings suggest that although the literature indicates high "dropout" rates or non-compliance with treatment, families do not drop out of services altogether; rather they leave particular providers for what are reported to be valid reasons. For example, families in the study reported little or no choice of providers. Policies that support a greater selection of both providers and services are needed. In the absence of policies that promote choice, policies must support an agency's ability to provide flexible hours and location of services. Also, providers need to pay far greater attention to the reasons given for leaving services. For example, providers need to devote more attention to improving the experiences of families at intake to ensure they receive an effective link to necessary services.

"I want to continue with all the therapy; the OT, PT, and speech because it is helping him so much, and they will let me know when he's done."

"One of us had to stay home to meet all her medical needs. And I chose to stay home…"

What the Research Says

Decision–making is a complex phenomenon and the research examining decision-making is often equally as complex. The real world decisions families must make when a child has an emotional or behavioral disorder are complicated by the complexities of the service system they must engage and navigate. In order to examine these complexities and provide families with better informed choices, new statistical approaches are being developed using outcome data to help improve the way clinical decision-making is made in recommending and providing mental health services to children and adolescence (Lyons et al., 1997).

It is also impossible to separate decision-making from issues regarding access and barriers to treatment. Research is increasingly examining the perception of families about barriers to participation in treatment (Kruzich et al., 2003). Kazdin and associates (1997) produced a comprehensive list of barriers to treatment participation. These barriers were listed under five major categories:

1) stressors and obstacles that compete with treatment
2) treatment demands and issues
3) perceived relevance of treatment
4) relationship with the therapist and
5) critical events.

In a separate study, Kazdin and associates (1997b) found that parent perceptions of the difficulties of participating in treatment influenced who dropped out of treatment. In other research examining the effects on expectations and attendance, it was found that parents were more prepared for their child's psychotherapy when expectations and treatment were discussed (Shuman & Shapiro, 2002).

The life situation of a family may be altered in many ways when a child has a chronic condition and requires special needs. Patterson, (1996) examined how decisions and changes made in one part of a family system affects the whole family. In one study looking at the impact of losing the benefits provided by Supplemental Security Income (SSI) and the decisions made following the discontinuing of the benefit, it was found that families made many difficult and life altering decisions. For example, one family with limited financial means had to choose whether to provide health care for one of their children or a roof over the family's head. Another family had to decide whether to stay married or to get divorced in order to qualify for SSI benefits (Lazear & Worthington, 2001). The effects of the stress of parenting a child with serious emotional or behavioral disorders can be great. Research suggests that a parent's level of stress can have an impact on their reporting of child behavior problems (Kerivan-Marks, 2002).

Cascade Effect

John (Age 16) Loses SSI Benefit

No Longer Sees Psychiatrist — Mom Returns to Work — Dad Increases Work Hours

Sibling Counseling

Increased Stress Level

Beats Up Brother With Medical Issues

Damages Property

Medication Needed for John — Brother Needs Medical Treatment

$

Damaged Property Needs Repair — Pay Rent

Loss of Home

Housing Plan B

Family Moves

Critical Family Supports

◼ = Strategic Areas of Support & Intervention

Loss of Established Formal Supports — Loss of Established Informal Supports — Increased Stress on Entire Family

In the **SSI Family Impact Study**, changes in the SSI benefit policy afected multiple dimensions of the family's life that went way beyond the obvious financial ramifications, causing a "cascade effect" which resulted in dramatic changes in the family's life (Lazear & Worthington, 2001).

Employment is another example of a family's life domain that may be changed when a child has a serious disorder. Research is showing that despite the ingenuity of families in adapting their lives, many barriers exist to obtaining and maintaining employment and caring for a child with special needs (Rosenweig et al., 2002). With jobs on the line, or loss of income, families often find themselves in debt from paying health care and related costs, such as transportation and childcare. Research on poverty and its impact on a family's quality of life finds poverty increases stress which can lead to greater risks of mental health difficulties (Park et al., 2002). Costello and associates (2003) examined the rates of psychopathology for Cherokee Indian children before and after a change in economic status and found that poor children were more likely than their non-poor counterparts to have a psychiatric diagnosis. In light of findings such as these, the decisions for caregivers to remain in or give up employment become even more difficult. Research also suggests that a parent's level of stress can have an impact on their reporting of child behavior problems (Kerivan-Marks, 2002).

For families in ethnic and racial minority groups in the United States, disparities in health care are seen at every level, from physical to mental health, and affect the decisions many minority families
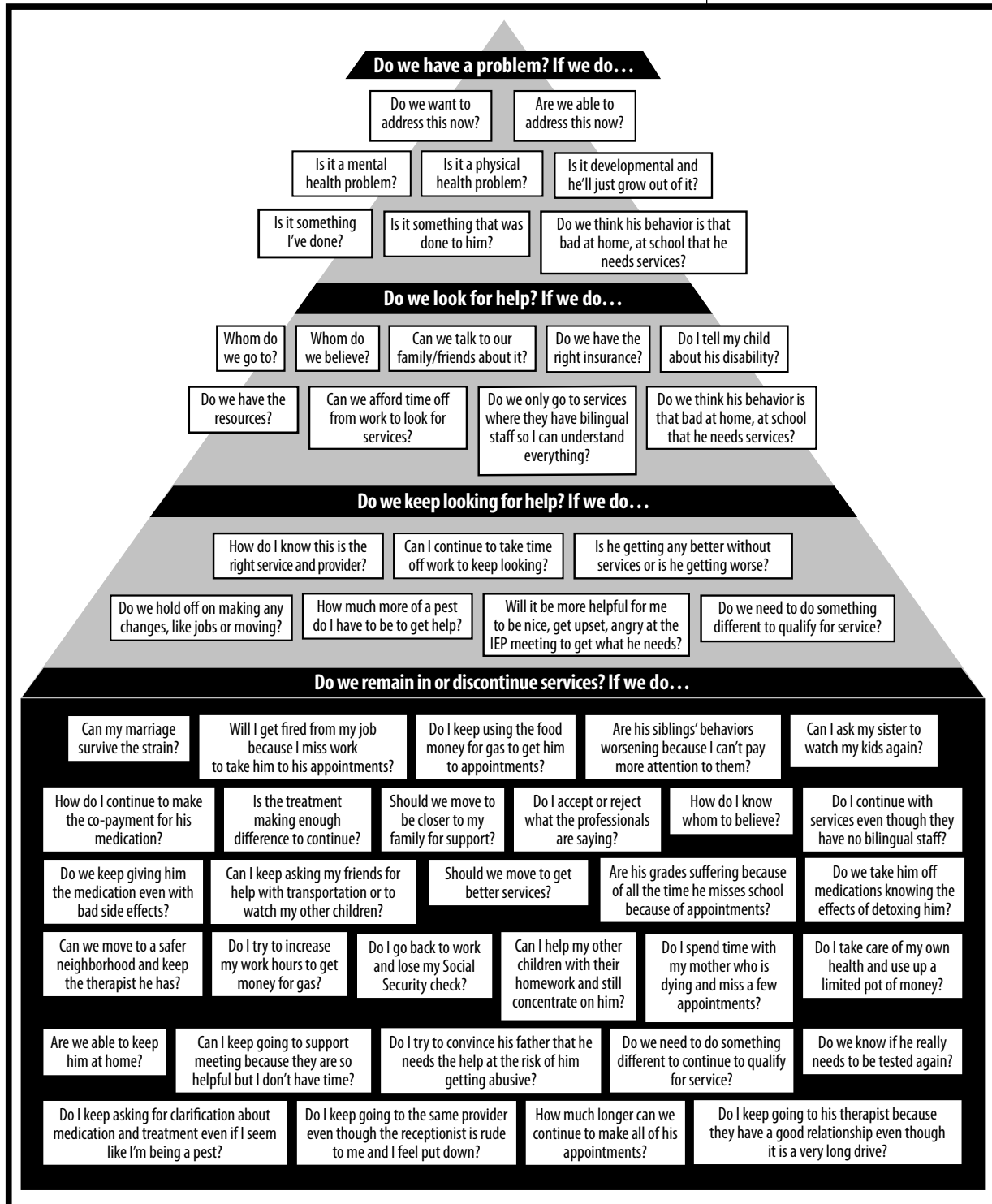
make (Sue et al., 1991; Takeuchi et al., 1993); Viale-Val et al., 1984). These disparities exist even when insurance status, income, age and severity of the condition are comparable (Nelson, 2002). Torkarski (2002) explains one of the reasons for this disparity is that while multi-generational poverty and traumatic experiences put a higher burden on African Americans and Hispanics who need mental health services, they may feel stigmatized if they seek them. She also cites former Surgeon General Satcher, who reported that in some groups mental illness can be perceived as a character weakness or failure of their spiritual faith, giving as an example Asian Americans who may have a difficulty accepting the notion of mental health services and are 25% as likely as Whites to seek care. African Americans are 50% as likely to seek care (Tokarski 2002).

Other studies have found that Hispanic and African American children leave mental health services prematurely more often than do Caucasian children (Sue et al., 1991; Takeuchi et al, 1993; Viale-Val et al., 1984) Other reasons for the disparity include lack of insurance (30% of Hispanics are likely to be uninsured), mistrust of the health system, language barriers, racism and prejudice as stressors and lack of access to mental health services (Danar, 2002; Lie, 2004; Franklin, 2003; Sam, 2004; Tokarski, 2002).

A growing body of literature is focused on the decision-making process as researchers, service providers and families recognize the central role that decisions play in providing mental health services and supports for children and their families. Some of the literature focuses on clinicians, offering principles and strategies to help them make the best decisions for the children and families they serve (Bioethics Committee, Canadian Paediatric Society (2004). Research examining the impact of pediatricians and teachers suggests these groups play an important role as catalyst in parents' perceptions that their children need services (Poduska, 2000). Other literature is focused on helpful strategies for parents and caregivers to sort out the issues about obtaining mental health care (National Institute for Mental Health, 2004; National Mental Health Information Center, 2000; Parent Advocacy Coalition for Educational Rights, 1996; Goodman, 2000).

However, a consistent theme in the current literature is the absolute necessity for families to be involved in decisions affecting them, whether it is with a single service provider or as a member of a team. Families in the study found themselves making decisions about services and treatment based on both limited knowledge and limited choices. Heflinger and Bickman (1996) emphasized the importance of choice for families, not only service treatment choice, but also choice in the level of parent participation in treatment. Families must be able to make decisions from a position of strength, equipped with current knowledge about the most effective practices and availed of choice.

Decisions, Decisions, Decisions

Do we have a problem? If we do…

Do we want to address this now?

Are we able to address this now?

Is it a mental health problem?

Is it a physical health problem?

Is it developmental and he'll just grow out of it?

Is it something I've done?

Is it something that was done to him?

Do we think his behavior is that bad at home, at school that he needs services?

Do we look for help? If we do…

Whom do we go to?

Whom do we believe?

Can we talk to our family/friends about it?

Do we have the right insurance?

Do I tell my child about his disability?

Do we have the resources?

Can we afford time off from work to look for services?

Do we only go to services where they have bilingual staff so I can understand everything?

Do we think his behavior is that bad at home, at school that he needs services?

Do we keep looking for help? If we do…

How do I know this is the right service and provider?

Can I continue to take time off work to keep looking?

Is he getting any better without services or is he getting worse?

Do we hold off on making any changes, like jobs or moving?

How much more of a pest do I have to be to get help?

Will it be more helpful for me to be nice, get upset, angry at the IEP meeting to get what he needs?

Do we need to do something different to qualify for service?

Do we remain in or discontinue services? If we do…

Can my marriage survive the strain?

Will I get fired from my job because I miss work to take him to his appointments?

Do I keep using the food money for gas to get him to appointments?

Are his siblings' behaviors worsening because I can't pay more attention to them?

Can I ask my sister to watch my kids again?

How do I continue to make the co-payment for his medication?

Is the treatment making enough difference to continue?

Should we move to be closer to my family for support?

Do I accept or reject what the professionals are saying?

How do I know whom to believe?

Do I continue with services even though they have no bilingual staff?

Do we keep giving him the medication even with bad side effects?

Can I keep asking my friends for help with transportation or to watch my other children?

Should we move to get better services?

Are his grades suffering because of all the time he misses school because of appointments?

Do we take him off medications knowing the effects of detoxing him?

Can we move to a safer neighborhood and keep the therapist he has?

Do I try to increase my work hours to get money for gas?

Do I go back to work and lose my Social Security check?

Can I help my other children with their homework and still concentrate on him?

Do I spend time with my mother who is dying and miss a few appointments?

Do I take care of my own health and use up a limited pot of money?

Are we able to keep him at home?

Can I keep going to support meeting because they are so helpful but I don't have time?

Do I try to convince his father that he needs the help at the risk of him getting abusive?

Do we need to do something different to continue to qualify for service?

Do we know if he really needs to be tested again?

Do I keep asking for clarification about medication and treatment even if I seem like I'm being a pest?

Do I keep going to the same provider even though the receptionist is rude to me and I feel put down?

How much longer can we continue to make all of his appointments?

Do I keep going to his therapist because they have a good relationship even though it is a very long drive?

Families made many decisions during the two years of the study. **Decisions, Decisions, Decisions** illustrates the layering of questions upon questions that families had to answer, and suggests the complexities of decisions families had to make as they sought, remained in or discontinued services.

System of Care Checklist: Decisions and Responsibilities of Care

Making decisions can be "easier" if…

☐ Parents have access to information about child development and behavior that can help them make decisions whether or not to seek an evaluation.

☐ Assessments are provided in a timely fashion so that families and providers can have information which, combined with what parents know, may help them recommend a course of treatment.

☐ Families understand how their child's health, social life, education, and development may be affected by the child's emotional or behavioral problems.

☐ Families feel comfortable asking questions of their physical or behavioral health care provider, school personnel, or other agency staff, and feel comfortable asking for second opinions.

☐ Families have access to a family organization that can provide information, services and support.

☐ Current and accurate information about services available and treatment options and alternatives is easily accessible to all families, providers, and the community, including pediatricians.

☐ Schools provide parents with on-going information about their child's behavior in school, such as peer and adult relationships and learning problems.

☐ While seeking services and during service planning and implementation, providers/care managers assist and support the family in examining all life domains that may impact service and treatment decisions.

☐ Parents know that the information they share about their child's development is respected and their lives will not be judged.

☐ Families know their privacy is protected, and when, how and why confidential information may be shared.

☐ The child is included in the decision-making process when appropriate.

☐ Families and service and support providers understand and address the barriers families face while seeking services and attempting to continue treatment and access services.

☐ Families are given information about specific ethnic or cultural groups that may impact the treatment decisions they make for their child, such as specific groups being over-represented in a program that has been recommended.

☐ Providers review their own processes with families for families to access service and treatment and make necessary changes or enhancements.

☐ Policies are in place which support a wide and varied selection of providers and services.

- ☐ Families have easy access to information about the credentials and expertise of the providers who may be or are working with their child.
- ☐ Agencies provide flexible hours and location of services.
- ☐ Agencies provide culturally competent treatment and services.
- ☐ Families have the opportunity to provide feedback about individual treatment providers and/or other agency staff, such as receptionists, who are in contact with families; and, individuals and agencies respond to it accordingly.
- ☐ Families have access to information about eligibility requirements for services and about their health care insurers.
- ☐ Families understand their right to advocate for their child, their right to refuse treatment for their child, and the process to make a formal complaint without penalty or retribution.
- ☐ Services are coordinated across agencies and providers who communicate effectively with family, youth and each other.

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